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Cancer survivors are known to experience significant changes to psychosocial wellbeing (e.g., Everdingen et al., 2007; Houldin, 2000). In particular, cancer is considered to be a highly impactful and traumatic event (Kállay, & Dégi, 2014; Kangas, 2013), and often contributes to negative changes in mental and emotional functioning. It has been projected that up to 50% of cancer survivors will experience impairment from mental health symptoms (Derogatis et al., 1983; Honda & Goodwin, 2004; Massie & Holland, 1990), with depression, being the most common, projected to affect 20-30% of cancer survivors (Honda & Goodwin, 2004; Irwin, Henderson, Knight, & Pirl, 2014).

Problematically, identification of psychosocial needs of cancer survivors within oncological care is lacking (Adler, Page, & Institute of Medicine, 2008; Holland et al., 2011; Nakash et al., 2014). Oncological primary care providers may often fail to identify psychosocial needs of cancer survivors (Forsythe et al., 2013; Söllner et al., 2001), resulting in unmet psychosocial needs and a lack of mental health referrals (Nakash et al., 2014). Researchers have identified the need for improvements in assessment of psychosocial needs of cancer survivors as a critical step in reducing gaps in psychosocial care (Adler et al., 2008). Biopsychosocial models, which theoretically include physical, emotional, social, and functional health factors (Engel, 1980; Hatala 2012), have been identified as particularly salient in assessing holistic wellbeing of individuals with chronic illnesses such as cancer (Sperry, 2006).

Currently, measures of quality of life (QoL) remain the most commonly utilized biopsychosocial assessment tools in cancer care (King & Hinds, 2012; Lavdaniti & Tsitsis, 2015). However, QoL and other biopsychosocial assessments utilized in medical care have been criticized for bias towards the measurement of bio-medical functioning (Jacob, 2013; Moons, Budts, & De Geest, 2006), and may fail to appropriately assess psychosocial factors—particularly those relevant to co-occuring mental health symptoms (Adler et al., 2008; Alonso, 2004; Connell, O'Cathain, & Brazier, 2014). Alternatively, wellness-based models, biopsychosocial models commonly utilized in psychosocial health professions, are generally more inclusive of psychosocial factors, and may provide a more robust assessment of cancer survivors' psychosocial needs (Jamner & Stokols, 2000; Myers et al., 2005a; Swarbrick, 2013). Additionally, researchers have suggested the inclusion of patient feedback in improving disciplinary conceptualization of wellbeing (Connell et al., 2014; Weston, 2005), as QoL and wellness are theoretically subjective concepts of health (Sirgy, 2012). To this end, the purpose of this research study was to examine connections between multidisciplinary frameworks of wellbeing, QoL and wellness, and their ability to assess significant psychosocial factors that impact the holistic wellbeing of cancer survivors. This study also compared multidisciplinary models of wellbeing to significant psychosocial factors identified by cancer survivors.

In the current study, both of the examined models of biopsychosocial wellbeing were found to account for significant variance in depression scores among cancer survivors. Additionally, both models were found to have significant commonality, as well as unique contributions in predicting depression among cancer survivors. These findings

suggest the utility of multidisciplinary inspection of biopsychosocial assessment models for use in cancer care. Furthermore, whereas the QoL assessment model was found to be superior in capturing the unique social and physical needs of survivors within the cancer context, the wellness model was found to contribute a unique construct to the overall biopsychosocial model of wellbeing: coping styles. Qualitative analysis of semi-structured interviews held with eight cancer survivors resulted in the identification of additional salient psychosocial factors among cancer survivors not present in either of the models; namely, items related to post-traumatic growth, satisfaction with health providers and settings, and the impact of cancer-related financial burden. The qualitative results also provided further support for the quantitative results. Although it is clear that current assessment models utilized in biomedical and mental health settings provide reasonable utility in accounting for the psychosocial needs of cancer survivors, the results of this study indicate the need for further refinement of biopsychosocial models utilized in the cancer context. Interdisciplinary inspection, as well as further analysis of the self-identified needs of cancer survivors may contribute to the creation of more robust biopsychosocial assessment models of wellbeing, and the resultant improvement of psychosocial care for cancer survivors. Furthermore, implications for theory, mental health and biomedical practice, and suggestions for future research will be shared while taking into consideration relevant literature on cancer survivorship.

SIGNIFICANT PSYCHOSOCIAL FACTORS RELATED TO HOLISTIC WELLBEING AMONG CANCER SURVIVORS: A MIXED-METHODS EVALUATION

by

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CHAPTER I

INTRODUCTION

Cancer is considered one of the leading causes of death worldwide, accounting for one in four deaths in the United States (Centers for Disease Control and Prevention, 2016a). Approximately 1.7 million new cases were expected in the United States in 2017 (American Cancer Society, 2017), and the number of new global cases is expected to rise 70% over the next two decades (World Health Organization, 2015). Treatment for cancer has become, and will remain, a top global health priority. Fortunately, advances in biomedical cancer treatment over the last decade have resulted in dramatically increased survivorship rates for individuals diagnosed with cancer (Adler, Page, & Institute of Medicine, 2008). As success in biomedical treatment for cancer continues, increased attention has been shifted to psychosocial wellbeing for cancer survivors (e.g., Adler et al., 2008; Chambers et al., 2014; Grassi & Riba, 2014; Holland, Watson, & Dunn, 2011).

Developments in research of wellbeing and quality of life of cancer survivors have yielded multiple findings that may be used to improve the current state of cancer care. Cancer survivors - who include all individuals from the time of diagnosis throughout the rest of the individual's life, including those currently diagnosed with cancer and receiving treatment (Centers for Disease Control and Prevention, 2016b) - are known to experience significant changes to both physical and psychosocial wellbeing (Adler et al., 2008; Everdingen et al., 2007; Houldin, 2000). Psychosocial stressors

experienced by cancer survivors have been linked to decreased treatment adherence, decreased utilization of oncological resources, increased suffering, decreased survival odds, and decreased quality of life for patients and family members (Adler et al., 2008). Thus, psychosocial interventions for cancer survivors and their families dealing with cancer related stressors are equally important to medical care of cancer symptoms (Adler et al., 2008; Houldin, 2000; Nekolaichuk, Turner, Collie, Cumming, & Stevenson, 2013).

Additionally, psychosocial wellbeing is closely related to mental health outcomes among cancer survivors (Nakash et al., 2014; Torta & Ieraci, 2013). Positive psychosocial wellbeing is predictive of Post Traumatic Growth (PTG) (e.g., Shand, Cowlishaw, Brooker, Burney, & Ricciardelli, 2015); conversely, acute psychosocial distress is predictive of comorbid mental health disorders (e.g., Jacob, 2013; Kállay, & Dégi, 2014). It has been projected that up to 50% of cancer survivors will experience impairment from mental health symptoms and need mental-health services (Derogatis et al., 1983; Honda & Goodwin, 2004; Massie & Holland, 1990; Nakash et al., 2014). Mental health difficulties are considered impactful both during and after cancer treatment, and have been associated directly with level of disability, advanced illness, and pain (Nakash et al., 2014). Depression, which includes symptoms of low mood and functional impairments (American Psychiatric Association, 2013), is considered the most common mental health disorder among cancer survivors and is projected to affect 20-30% of cancer survivors (Honda & Goodwin, 2004; Irwin, Henderson, Knight, & Pirl, 2014). Depression also is thought to significantly impact cancer survivor wellbeing (Breitbart, Rosenfeld, Pessin, & Kaim, 2000) and has been linked to decreased survival

rates (Meyer, Sinnott, & Seed, 2003). Treatment for cancer survivors with depression optimally includes pharmaceutical intervention (i.e., antidepressants) in conjunction with counseling or psychotherapy (U.S. Department of Health and Human Services, National Institutes of Health, National Institute of Mental Health, 2002).

Problematically, assessment and treatment of mental health within oncological care is lacking. In a recent comprehensive study of oncological psychosocial care sponsored by the National Research Council (NRC) and the National Academy of Medicine (formerly the National Institute of Medicine), cancer survivors and their families consistently reported feeling they had received inadequate support for emotional and mental health needs during their cancer treatment and beyond (Adler et al., 2008). Factors that contribute to low rates of psychosocial screening within cancer programs include lack of training to detect psychosocial distress among oncologists and nurses, limitations in time allotted to practitioners for patients visits, and lack of psychosocial professionals within cancer programs (Adler et al., 2008). Medical care providers are crucial first-responders in the identification of psychosocial distress among cancer survivors (Hawk, 2002; Nakash et al., 2014). Ideally, patients needing psychosocial services, ranging from general psychoeducation, support groups, and individual counseling services (Adler et al., 2008), would be identified by medical care providers and referred to appropriate services (Miovic & Block, 2007). However, psychosocial distress is not recognized easily among nurses (Mitchell, Hussain, Grainger, & Symonds, 2011), oncologists (Söllner et al., 2001), and general care providers (Mitchell, Rao, & Vaze, 2011), resulting in misassessment (Söllner et al., 2001) and lack of needed referrals

psychosocial treatment (Nakash et al., 2014). Approximately 59% of cancer survivors have reported seeking psychoeducation and/or referrals for mental health concerns from their oncological or primary physician; however, the majority of these patients were not provided additional referrals for mental health needs (Nakash et al., 2014). Nearly 55% of cancer survivors report having no discussion with their oncologists about their psychosocial and mental health needs (Forsythe et al., 2013), despite established standards of care prompting providers to initiate these discussions as routine oncological treatment (Adler et al, 2008; Holland et al., 2011). Additionally, cancer survivors may not know how to communicate their feelings or be aware of their distress (Mehnert, Lehmann, Cao, & Koch, 2006).

Researchers and medical practitioners alike have increasingly noted the need for more services of mental health providers to fill gaps in psychosocial care (Adler et al., 2008; Barre, Padmaja, Saxena, & Rana, 2015; Grassi & Riba, 2014). Two major national level committees tasked with reviewing standards of quality cancer care, the Committee on Psychosocial Services to Cancer Patients/Families in Community Settings (Adler et al., 2008) and the American Psychosocial Oncological Society (Holland et al., 2011), have strongly recommended increased priorities around availability, referrals, and funding for mental health experts within oncology. Holland, Watson, and Dunn (2011) noted that these recommendations of quality standards have been made previously, yet researcher recommendations rarely have translated to changes in practice.

In order to close current treatment gaps of psychosocial health among cancer survivors, researchers have suggested three major barriers that must be addressed. First,

continued stigma around mental health issues attendant with psychosocial distress may significantly contribute to inadequate psychoeducation and mental health referrals from medical providers (Adler et al., 2008; Holland et al., 2011). Psychosocial needs, such as emotional distress, continue to be regarded as optional, if not as luxury, in the medical community (Adler et al., 2008; Hermann, Saxena, & Moodie, 2005). Medical professionals traditionally practice out of the biomedical model, which is geared towards identifying disease pathology and ameliorating it (Jamner & Stokols, 2010). However, psychosocial needs are not adequately conceptualized from a medical model framework, as psychosocial health often involves multiple complex factors that interact subjectively (Jacob, 2013). Advocacy for changes in practice to include assessment and treatment of psychosocial health is critical, and may be accomplished through the increased participation of mental health professionals in multidisciplinary care settings and research.

Second, it has been suggested that a major barrier to integrated psychosocial treatment in cancer care includes "no way to query psychosocial needs quickly in daily practice…" (Holland et al., 2011). The use of multi-dimensional assessment tools, which include psychosocial domains, has been suggested as a key tool in improving coordination of integrated treatment efforts between medical and mental health care providers (Adler et al., 2008; Grassi et al., 2015). Though psychosocial needs are complex to conceptualize, the last few decades have shown burgeoning development of assessment models that ideally capture psychological, social, and biomedical aspects salient to a patient's wellbeing (Hatala, 2012). Biopsychosocial assessment tools, though

still in their nascency, are intended to identify significant leverage points in treatment planning for biological, social, and psychological determinants of health (Hatala 2012; Jones, Edwards, & Gifford, 2002; Sperry, 2006). Integrated or holistic biopsychosocial models are particularly appropriate for cancer survivors, as biomedical and psychosocial factors are often closely intertwined and may not be appropriately understood if singularly assessed (Shapiro et al., 2001; Hatala, 2012; Alonso, 2004). Measures of quality of life, a concept closely associated with wellbeing (Miller & Foster, 2010), remain the most widely used biopsychosocial assessment tools in cancer care (King & Hinds, 2012; Lavdaniti & Tsitsis, 2015). However, biopsychosocial assessments utilized in medical care have been criticized for bias towards the measurement of bio-medical functioning (Jacob, 2013), and may fail to appropriately assess psychosocial factors relevant to holistic treatment planning (Alonso, 2004; Carr, Higinson, & Robinson, 2003). Failure to adequately assess psychosocial factors, which are predictive of mental health, will contribute to continued gaps in psychosocial care of cancer survivors.

Third, while a multitude of researchers have affirmed the significance of psychosocial wellbeing in cancer survivorship, a lack of research integration may complicate progress in converting researcher recommendations into changes in practice. Oncological and wellbeing research is spread across multiple fields that include public health, psychiatry, psychology, social work, epidemiology, pharmacology, and mental health counseling. In a recent article, Chambers et al. (2014) noted the confusing amalgamation of research generation in cancer care from multiple disciplines, and highlighted a lack of common language and use of common models across health

disciplines as a major barrier to research translation in clinical practice. To help fill gaps in research and oncological care, it may be critical for researchers to explore relationships between multi-disciplinary psychosocial models and constructs as a means of fostering the development of established multidisciplinary paradigms and effective communication between professions.

In this chapter, psychosocial and holistic wellbeing will be described. Multidisciplinary assessment models of holistic wellbeing that have been utilized to assess biomedical and psychosocial factors are also presented. Subsequently, the purpose of this study and the research questions are identified. The chapter concludes with a discussion of the significance of the study, definitions of terms included in the research, and a description of the organization of the study.

Holistic Wellbeing

The World Health Organization has defined health as a multidimensional state including physical, mental, and social wellbeing, not just the absence of disease and disability (WHO, 1948). Through this definition, we may begin to understand wellbeing as a multidimensional construct that describes a graded, summative state of health. A review of literature on wellbeing and wellness, terms often used interchangeably, defines wellbeing as a framework that views individuals within a holistic perspective that prioritizes the interconnectedness of multiple dimensions including psychological, social, spiritual, and physical factors (Miller & Foster, 2010). However, some conceptualize wellness as the active process in which one pursues optimal wellbeing (Cardinal &

Krause, 1989; Leach, 2004). For the purpose of this study, the term wellbeing will be used when referring to wellness or wellbeing research.

Models of wellbeing are often holistic in scope, and prioritize integration of multilevel factors rather than the bifurcation of biological, psychological, and social factors (Myers & Sweeney, 2005a). Public health expert Leonard Duhl (1996) described a holistic view of wellbeing as "…a ball of interconnected strands that could be picked up at any point, and a relationship to all other issues, institutions, people, and places would exist" (p. 259). Holistic models are inherently multidisciplinary and often " attempt to dismantle conceptual borders between the biological and psychological, nature and nurture, or science and spirituality" (Hatala, 2012, p. 53). Comprehensive research on holistic wellbeing models should ideally incorporate multidisciplinary researcher literature related to connections between biological, social, and psychological health determinants.

Whereas the breadth of holistic models seek to capture the true multidimensionality of wellbeing, the applications of holistic models in research have been criticized for their overwhelming intricacy (Jamner & Stokols, 2010; Sirgy 2012). It has been suggested that researchers utilizing holistic models of wellbeing prioritize factors, according to relevant literature, in order to retain clarity of researcher findings (Jamner & Stokols, 2010). By the same token, biopsychosocial research that fails to be holistically integrative in scope has been criticized for overly dichotomizing biological, psychological, and social factors (Tavakoli, 2009), and possibly masking an underlying biomedical approach (Alonso, 2004; Hatala, 2012). Increased utilization of integrative or

holistic research designs may strengthen biopsychosocial researcher findings within biomedical and mental health research (Hatala, 2012). Researchers utilizing holistic models of wellbeing should make thoughtful choices in navigating tensions between over-complexity and appropriate representativeness of wellbeing determinants.

Furthermore, unlike disease models that prioritize negative functioning, models of wellbeing should theoretically account for both negative and positive factors of wellbeing. The identification of positive factors of wellbeing is thought to bolster patient empowerment in the pursuit of wellness (Swarbrick, 2013). A wellbeing approach to health care also is aimed at improving quality of life (Miller & Foster, 2010; Swarbrick, 2013) and disease prevention (Witmer & Sweeney, 1992). As previously discussed, the significance of psychological and social—psychosocial—factors are key intervention points for improving holistic wellbeing among cancer survivors.

Psychosocial Wellbeing

Psychosocial wellbeing may be understood as an individual's capacity to "perform activities of daily living and to engage in relationships with other people in ways that are gratifying to him and others, and that meets the demands of the community in which the individual lives" (Mehta, Mittal, & Swami, 2014, p.1). Psychosocial wellbeing encapsulates a wide range of psychological and social health factors, and is a subset of holistic wellbeing (Adler et al., 2008). Additionally, psychosocial wellbeing is an important framework for conceptualizing mental health. Psychosocial adversity is thought to cause mental distress and mental health disorders (Jacobs, 2013). While any range of health professionals may assess psychological and social needs, treatment of

psychosocial needs often includes mental health service providers such as psychologists, psychiatrists, counselors, and social workers (Jacobs, 2013; National Alliance on Mental Illness, n.d.). Psychosocial treatments include different types of psychotherapy and counseling, and are aimed at providing support, psychoeducation, and guidance for individuals with mental health difficulties (NAMI, n.d.).

Individual psychosocial wellbeing is often significantly impacted during the course of the cancer experience (Adler et al., 2008; Forsythe et al., 2013). Psychosocial stressors related to receiving a cancer diagnosis and undergoing cancer treatment vary in intensity for individual patients, although common stressors for cancer survivors include existential concerns, anticipatory grief, concerns about the impact of their cancer on their families and friends, coping with the intensity of cancer symptoms and treatments, loss of control over daily activities and abilities, fears of emotional difficulties after treatment completion, and/or reoccurrences (Houldin, 2000). As previously stated, psychosocial distress has been linked to critical medical outcomes, including decreased treatment utilization, poorer prognosis, and comorbid mental health pathology (Barre et al., 2015; Nakash et al., 2014).

The need for improved assessment of psychosocial wellbeing has been noted in cancer care (Adler et al., 2008), as well as in general health care (Jacob, 2013). Specifically, refinement of assessment models that evaluate (a) psychosocial context, (b) stress, (c) supports, (d) resources, and (e) coping should ideally inform mental health diagnosis and management (Jacob, 2013). Furthermore, assessment of psychosocial factors in biomedical contexts should not approach psychosocial factors as wholly

separate from biomedical factors (Tavakoli, 2009); rather, models utilized should provide holistic assessment of psychosocial and biomedical health in tandem.

Quality of Life

Quality of life (QoL) may be defined as "patient's appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal" (Cella & Cherin, 1988, p. 70). As previously stated, measures for quality of life remain the most widely used means of assessing holistic needs of cancer survivors (King & Hinds, 2012; Lavdaniti & Tsitsis et al., 2015). Theoretically, QoL includes a host of constructs, most commonly physical, psychological, spiritual, and social wellbeing, that influence and comprise one's overall wellbeing –many of which are subjective in nature and vary in importance from person to person (Lavdaniti & Tsitsis 2015; Sirgy, 2012). Quality of life is a dynamic concept, and has been linked to holism in that its parts also affect each other as well as the sum (Carr, Higginson, & Robinson, 2003). Health fields such as nursing have recognized the appropriateness of measuring QoL, as "cancer and its treatment impact the entire patient, including physical, psychological, social, and spiritual wellbeing…" (King & Hinds, 2012, p.9). Theoretically, QoL is closely tied to concepts of wellbeing (Miller & Foster, 2010).

However, despite the fact that QoL has theoretical roots in the psychological tradition (Sirgy, 2012) that values subjective meaning making, current QoL research is often more closely tied to the medical model, which often focuses on the measurement of physical and mental decline and impaired role and social functioning (Carr et al., 2003). Current QoL oncology research is further complicated by the common use of *health*

related quality of life (HQoL) theory and assessment. HQoL research was developed initially to assess of the impact of disease and its treatment across dimensions of social, physical, psychological, and somatic functioning (Revicki et al., 2000**).** Emphasis on disease impacts upon functioning prioritizes impairment, and may bifurcate and undervalue the importance of psychosocial factors such as emotional wellbeing. Though the development of HQoL as theoretically distinct from QoL was intended to demarcate an emphasis on biomedical functioning research, virtually no distinction between HQoL and QoL exists within current health research and assessment (Fayers & Machin, 2007).

Although intended to be holistic in scope, QoL assessment within cancer care has been criticized as being overly dependent on assessment of health related functioning (Carr et al., 2003; Lavdaniti & Tsitsis, 2015). The authors of the most widely used cancer related QoL questionnaire, the FACT-G (Cella et al., 1993), have remarked that increased study of the multidimensional nature of QoL would greatly benefit QoL measurement, particularly in psychology related fields. Similarly, recent work across multiple fields has suggested the need for improved sensitivity of QoL assessment in capturing mental health factors (Connell, O'Cathain, & Brazier, 2014) and other subjective factors relevant to holistic wellbeing (Carr et al., 2003; Moons, Budts, & De Geest, 2006).

Wellness

In the field of professional counseling, models of wellness most closely align conceptual frameworks of QoL. Wellness may be defined as "a way of life oriented toward optimal health and well-being, in which body, mind, and spirit are integrated by the individual to live life more fully within the human and natural community. Ideally, it

is the optimum state of health and well-being that each individual is capable of achieving" (Myers, Sweeney, & Witmer, 2000, p. 252). Wellness may be considered the action that leads to QoL. Wellness theory historically has been aligned more with the psychological tradition, which operationalizes wellbeing in terms of one's subjective evaluation of life satisfaction (Hattie, Myers, & Sweeney, 2004). Wellness theories in counseling have already been utilized successfully to guide psychosocial care of cancer survivors (Shannonhouse et al., 2014).

Although QoL and wellness are similar constructs, their association with different professional perspectives results in using different measurements, divergent constructs, and possible inconsistent perspectives of wellbeing. These differences, if explored, may highlight the unique contributions mental health and medical disciplines have to offer in the pursuit of improving psychosocial care for cancer survivors. Wellness-based assessment, which includes multiple input and output domains related to subjective experiences of emotional, mental, and social wellbeing (Myers et al., 2000), may provide more robust and nuanced assessment of psychosocial needs and general wellbeing of cancer survivors, while tradition oncological QoL assessments may be relied upon for more nuanced understandings of the specific effects of disease and treatment on mental, emotional, and physical functioning (Revicki et al., 2000). Additionally, increased inclusion of psychosocial constructs in cancer-related biopsychosocial measures might improve assessment utility in integrated treatment planning and mental health care (Grassi et al., 2015; Hattie et al., 2004).

Similarly, it may be critical to consider patient perspectives in prioritizing treatment of psychosocial factors of wellbeing. Patient feedback widely supports researcher findings that indicate a lack of adequate psychosocial care in oncology (Adler et al., 2008). As previously mentioned, currently models of QOL used in cancer care are often biased to a medical model, which prioritizes bio-medical health factors and simplify mental health and subjective constructs. Theoretical wellness and QoL both complicate the medical definition of health by expanding the meaning of health to include personal happiness, or *eudaimonia* (Larson, 1999; Miller & Foster, 2010; Sirgy, 2012). Eudaimonia is a Greek term utilized in positive psychology that translates to "flourishing, well-being, success, or the opportunity to lead a purposeful and meaningful life" (Sirgy, 2012, p. 7). Although a medical model of health is objectively measurable, a wellness view of health comprises a biomedical facet of wellbeing *in addition* to uniquely personal, subjective experiences of what wellness "feels like" (Miller & Foster, 2010). At their core, wellness and QoL must define health from the subjective viewpoint of each individual; these definitions of health must include personal meaning making and values that are specific to individual culture and context. Wellness and QoL researchers must accept this ambiguity, and should optimize methods that account for this variability.

To increase the presence and utility of mental health services within cancer care, counselors will need to account for shared and differing perspectives among multi-disciplinary health professionals in treatment planning. As counselors continue to find an increasing presence in medical settings, or in working with referred patients from medical settings, continued exploration of shared concepts in wellness and QoL frameworks will

increase understanding and effective communication in multi-disciplinary treatment planning, as well as empower counselors to advocate for the holistic wellness of their patients.

Statement of the Problem

As it is projected that 41% of American adults can expect a cancer diagnosis in their lifetime (American Cancer Society, 2016a), reductions in psychosocial treatment gaps are a significant priority. Mental health difficulties, most commonly depression, are often a direct result of untreated psychosocial distress. Barriers related to closing treatment gaps in psychosocial care include lack of attention to psychosocial and psychological constructs in assessment (Adler et al., 2008; Holland et al., 2011) as well as lack of integration of multidisciplinary research (Chambers et al., 2014). Identifying salient psychosocial factors in cancer survivorship is critical to the improving psychosocial care among cancer survivors. Models of holistic wellbeing, which include psychosocial and biomedical factors may serve as critical tools in improving the assessment and treatment of psychosocial needs in cancer survivorship.

Purpose of the Study

The purpose of this research study is to explore connections between multidisciplinary frameworks of wellbeing, QoL and wellness, and their ability to assess significant psychosocial factors that impact holistic wellbeing among cancer survivors. In particular, this study will first explore the extent to which both models account for relevant psychosocial factors related to depressive symptomology, as depressive symptoms are considered to be among the most common cancer-related psychosocial

effects throughout every stage of the cancer journey. Second, this research study seeks to explore cancer patient perspectives on the significance and prioritization of psychosocial factors to guide multi-disciplinary professionals in psychosocial treatment.

Research Questions

The following research questions have been designed to test the extent to which multidisciplinary models of wellbeing assess relevant psychosocial needs among cancer survivors, with particular focus on depressive symptomology, and to compare current assessment models of holistic wellbeing to cancer survivor's self-identified psychosocial needs.

Research Question 1: Does QoL (operationalized by FACT-G second-order subscales: physical wellbeing, functional wellbeing, social wellbeing, and emotional wellbeing) or wellness (operationalized by the FFWEL-A second-order subscales: physical self, social self, coping self, essential self, and the creative self) explain more variance in depression scores among cancer survivors?

Research Questions 2: What shared and unique variance do QoL and wellness have when explaining depression scores?

Research Questions 3: What do cancer survivors perceive as salient psychosocial needs or factors currently and previously in treatment?

Research Question 4: Are current models (wellness, QoL) consistent with the identified salient psychosocial factors in the experiences of cancer survivors?

Significance of the Study

Current gaps in care of psychosocial wellbeing among cancer survivors include lack of treatment and resources for psychosocial distress and common co-occurring mental health disorders (Adler et al., 2008; Nakash et al, 2014). Psychosocial distress and mental health disorders can lead to multiple difficulties for cancer survivors, both personally and in relation to their health status (e.g., Fresche de Souza et al., 2014; Houldin, 2000; Meyer, Sinnott, & Seed, 2003). Psychosocial needs among those with chronic illnesses are best understood from a holistic integrated perspective (Barden, Conley, Young, 2015; Hatala, 2012; Shapiro et al., 2001).

Models of holistic wellbeing provide utility in identifying salient points of intervention in multidisciplinary care (Adler et al., 2008; Grassi et al., 2015), but may also become unnecessarily complex (Jamner & Stokols, 2010). Ideally, assessment models of holistic wellbeing should be congruent with the expertise of the treating health professional, as well as the subjective needs of the individual. Although models related to holistic wellbeing are currently utilized in cancer care, they are known to focus on physical functioning (Carr et al., 2003; Lavdaniti & Tsitsis, 2015), and may inadequately assess significant psychosocial factors that predict psychosocial distress and mental health difficulties. Models of holistic wellbeing that are more closely identified with mental health disciplines such as counseling may provide a more robust assessment of relevant psychosocial needs among cancer survivors. Additionally, wellbeing assessment models utilized in medical care may fail to represent the identified needs of the populations they serve.

In the current study, the researcher has examined medical and mental health based models of holistic wellbeing in their ability to predict common symptoms of psychosocial distress, specifically depression, in cancer survivors. Moreover, the researcher has examined the fitness of these assessment models to the psychosocial needs described by cancer survivors. Hence, there is the potential to begin the development of an empirical model of psychosocial assessment that identifies salient psychosocial factors in cancer survivorship. Furthermore, the refinement of psychosocial assessment in oncological may also lead to improvements in referrals and collaboration with mental health professionals to better meet psychosocial treatment needs of cancer survivors.

Definition of Terms

For the purposes of this study, the following definitions were used to operationalize key constructs and concepts.

Cancer Survivors include individuals who have been diagnosed with cancer, from the time of diagnosis throughout the rest of the individual's life (CDC, 2016).

Holistic Wellbeing refers to a summative state of health, consistent with the WHO health concept (1948), that prioritizes the interconnectedness of multiple dimensions including psychological, social, spiritual, and physical factors (Miller & Foster, 2010).

Psychosocial Wellbeing refers to an individuals capacity to "perform activities of daily living and to engage in relationships with other people in ways that are gratifying to him and others, and that meets the demands of the community in which the individual lives" (Mehta, Mittal, & Swami, 2014). Psychosocial wellbeing encapsulates a wide

range of psychological and social health factors, and is a subset of holistic wellbeing (Adler et al., 2008).

Quality of Life (QoL) refers to "patient's appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal"(Cella & Cherin, 1988, p. 70). For the purposes of this study, QoL will be measured utilizing the Functional Assessment of Cancer Therapy Scale (FACT-G) (Cella et al., 1993).

Wellness, as understood from the counseling perspective, is defined as "a way of life oriented toward optimal health and well-being, in which body, mind, and spirit are integrated by the individual to live life more fully within the human and natural community. Ideally, it is the optimum state of health and well-being that each individual is capable of achieving" (Myers, Sweeney, & Witmer, 2000, pg. 252). For the purposes of this study, wellness will be measured utilizing the the Five-Factor Wellness Inventory, Adult Form (FFWEL-A) (Myers & Sweeney, 2005a).

Depression is defined as is a common but serious mood disorder that is known to cause severe symptoms that affect how one feels, thinks, and handles daily activities (National Institute of Mental Health, 2016). For the purposes of this study, depression will be measured utilizing the Center for Epidemiologic Studies Short Depression Scale (CES-D-10) (Andersen, Malmgren, Carter, & Patrick, 1994).

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

Failure to address the psychological and social, or psychosocial needs among cancer patients is well noted throughout multiple disciplines of professionals within the world of oncology (e.g., Adler, Page, & the Institute of Medicine, 2008; Forsythe et al., 2013; Nakash et al., 2014). Although relative survival rates for cancer patients continue to increase as biomedical therapies for the disease improve, professionals across multiple health professions have discussed the resultant compromise of patient health as a direct outcome of current gaps in psychosocial care of cancer survivors (Adler et al., 2008; Chambers, Hutchinson, Clutton, & Dunn, 2014; Grassi & Riba, 2014; Holland, Watson, & Dunn, 2011).

Currently, a majority of oncological practitioners and researchers mistakenly conceptualize psychosocial factors as mere sequelae. Contrarily, multiple relationships are at play: psychosocial factors may contribute to cancer incidence (e.g., Kroenke et al., 2005), poorer cancer prognosis (e.g., Moreno-Smith, Lutgendorf, & Sood, 2010), and decreased survival rates (e.g., Meyer, Sinnott, & Seed, 2003). Similarly, the experience of cancer is thought to significantly impact psychosocial wellbeing and overall wellbeing or quality of life (e.g., Bellizzi, Miller, Arora, & Rowland, 2007; Chambers, et al., 2014; Pearman, 2003). The failure to address psychosocial factors and needs in cancer care

essentially decontextualizes the disease from multiple factors known to effect, and be effected *by* cancer, and limits the ability of multidisciplinary health providers to adequately attend to patients' holistic health and wellbeing. Additionally, the complex connections between psychological, social, and biological factors of health among cancer patients support the use of a holistic perspective in conceptualizing cancer survivor health needs.

Similarly, there exist particular gaps in psychosocial care for cancer survivors experiencing mental health related difficulties. It has been projected that up to 50% of cancer survivors qualify for a diagnosis of a mental health disorder, and are in need of mental health services (Derogatis et al., 1983; Honda & Goodwin, 2004; Massie & Holland, 1990; Nakash et al., 2014). Cancer is considered to be a highly impactful and traumatic event (Butler, Koopman, Classen, Spiegel, 1999; Kállay, & Dégi, 2014; Kangas, 2013), and often contributes to negative changes in mental and emotional functioning. As an example, depression is considered the most common co-occurring mental health disorder among cancer survivors, affecting 20-30% of cancer survivors (Honda & Goodwin, 2004; Irwin, Henderson, Knight, & Pirl, 2014). Assessment of broad psychosocial factors is thought to provide significant evidence for identifying and treating depressive symptoms (Torta & Ieraci, 2013); however mental health assessment, referrals, and treatment are considered to be severely lacking in cancer care (Holland et al., 2011; Nakash et al., 2014). Approximately 1.7 million new cases of cancer are expected in the US in 2017, and this number is expected to rise as much as 70% over the next two decades (World Health Organization, 2015). These statistics, as well as rising

survival rates for most cancer types, suggest that more people than ever will be *living* with the aftermath of cancer, which will include high rates of mental health impairment (Massie & Greenberg, 2005).

Though there exists prolific research related to the psychosocial needs of cancer survivors, evaluation of these needs within a holistic, multidisciplinary biopsychosocial framework is limited. This study will discuss relevant health models which impact current assessment and treatment practices within modern health care, and will seek to highlight the importance of holistic wellbeing models in understanding connections between various psychosocial factors and the experience of cancer. The following paragraphs will also explore the researcher literature on biopsychosocial effects related to the cancer experience, as well as current gaps in meeting cancer survivor health needs, with particular emphasis on mental health symptomology. An exploration of factors that currently contribute to the bifurcation of biomedical and psychosocial health care will also be presented. This section will conclude with a summarization of the findings from the review of relevant literature, and will reiterate the purpose of the study.

Models of Health

In addressing the known gaps in oncological care, and health care generally, it is critical to review models of health and wellbeing that guide health assessment and treatment. Similarly, it may be useful to understand the philosophical and historical backgrounds that inform current perspectives of wellbeing. In the case of cancer, trends in theoretical health models and practice over the last two centuries may provide

important clues to current gaps in treatment of psychosocial wellbeing among cancer patients and survivors.

Perspectives on health theory have changed dramatically across time, and changes in thinking are inextricably linked to medical practices. For example, early health theories of disease among ancient civilizations were often grounded by mysticism, and diseases were often attributed as punishments from the Gods. Health treatments included shunning unhealthy individuals from society, or providing sacrifices to the Gods to limit further diseases infliction (Porter, 1999). From the Roman Empire to the Middle Ages, medical thought was guided by humoural theory –with treatments that included blood letting, emetics, or purges of bodily fluids thought to control disease states (Porter, 1999). Although societal and scientific advancements have dramatically improved health care in the last few centuries, health practices will always be limited by the extent to which we understand and conceptualize health as a society.

The most commonly utilized model of health in modern research and practice is the biomedical model. However, researcher findings over the last few decades have led to the exploration of alternative models of health, including the biopsychosocial model, holistic wellbeing, and integrated models of health care delivery. This section will briefly review these health models and their role in future health research and practice.

Biomedical Model

The biomedical model found root in American health care during nineteenth century as a result of flourishing researcher findings of the biological causes of diseases – namely bacteria, nutritional deficiencies, and genetic influences (McGrady & Moss,

2013). Health as defined by the biomedical model is simply the "absence of illness" (Jones et al., 2005, p. 104). The traditional biomedical paradigm, or disease model, is thought to have its roots in the Cartesian dualism of the body and mind, which divides the mind as distinct from the body and conceptualizes disease as a failure within the *soma* (physical body) (Engel, 1977; McWhinney, 1986). Failures of the soma include illness related to inheritance (genetics), injury, and infection. The biomedical model is based on the classical science paradigm, which is reductionist, deterministic, and emphasizes an "average norm" as adequate in describing a phenomenon (McDaniel, Driebe, & Lanham, 2013).

In the 1800s and early 1900s, health care providers were primarily concerned with managing infectious diseases that were often acute and rapid. The contraction of these diseases, such as typhoid, pneumonia, smallpox, polio, and cholera, often came with a death sentence (Centers for Disease Control, 1999). A foundational model of health focused on the eradication of disease presence and causes proved efficacious in promoting population health. In fact, scientific advances in immunization and critical Public Health campaigns to raise awareness of infectious diseases in the mid twentieth century led to the minimization or eradication of these diseases in many cases (Centers for Disease Control, 1999). Yet, as immunization and public health campaigns helped drastically reduce infectious diseases, the face of health in the United States began to shift. Chronic and lifestyle related diseases –such as diabetes, heart disease, and cancer – slowly increased and replaced infectious diseases as the top health concerns. Unlike their infectious counterparts, the current leading heath concerns are significantly related to

psychosocial factors such as behavioral choices, diet, stress-related factors, and biopsychosocial conditions (McGrady & Moss, 2013).

As epidemiological, medical, and psychological research over the last century evolved, psychosocial factors were revealed as significant assets or determinants of health (Holland, 2002; Miller & Foster, 2010). Over the remaining course of the twentieth century, the need to understand non-biomedical health factors, such as health behaviors, internal motivation, and emotional coping, became increasingly apparent across multiple health disciplines. This is perhaps best reflected in the decision to define health, by the World Health Organization in 1948, as "a state of complete physical, mental and social well-being, and not merely the absence of disease" (World Health Organization, 1948). This landmark definition highlighted a conceptualization of health that moved beyond the disease/deficit model, but rather one that included a sense of total wellbeing in multiple life domains (Miller & Foster, 2010).

Despite changes in population health needs, and robust researcher findings supporting non-biological health determinants, the biomedical model has persisted as the dominant force in the American healthcare system for over a century (Deacon, 2013; Johnson, 2012). It has been criticized over several decades for its reductionist foundation that prevents it from accounting for all relevant aspects of health and illness (Armentrout, 1993; McWhinney, 1986), particularly psychological and social health determinants (Engel, 1977). Though it may be argued that the biomedical model has integrated psychological factors of determinants of health, mental disorders (which are known to affect biological functioning) are themselves understood as diseases caused by biological

dysregulation and defects in brain structure (Deacon, 2013). Ironically, biomedical researchers have failed to identify a strictly biological cause, or reliable biomarker, for any mental disorder (Deacon, 2013). Meanwhile, the majority of current diseases that pose a significant threat to societal health are lifestyle related, and are often attendant with chronic physical problems as well as emotional distress (McGrady & Moss, 2013). Despite the undoubted achievements of the biomedical model in managing particular forms of illness, biomedical practice is entrenched in a knowledge base that is no longer consistent with empirically-based understandings of health (Yuill, Crinson, & Duncan, 2010), and is inadequate in meeting current population health needs (Johnson, 2012; McGrady & Moss, 2013).

Biopsychosocial Model

The biopsychosocial model, first developed by psychiatrist George L. Engle in the late nineteen seventies, was created in response to critiques of the biomedical model. In particular, Engel explicitly warned of the biomedical model's inadequacy in regards to conceptualizing social and psychological aspects of health that were revealed to affect the illness process (Engel, 1980). The biopsychosocial model may be understood as "a way of understanding how suffering, disease, and illness are affected by multiple levels of organization, from the societal to the molecular" (Borrell-Carrió, Suchman, & Epstein, 2004). The biopsychosocial model, perhaps better conceptualized as a meta-theory (Biderman, Yeheskel, & Herman, 2005), was originally developed to assist non-psychiatric medical providers conceptualize patients as more than organisms with

diseases, but rather as individuals with complex behaviors and emotions that impact total health (Hatala, 2012).

The biopsychosocial model is currently adopted in various academic and institutional domains, including public health, preventative medicine, health education, and health psychology (Alonso, 2004; Tavakoli, 2009). It is now widely accepted that health status is the result of an interaction of biological, psychological, and social factors (Frankl, Quill, & McDaniel, 2003; Leigh & Reiser, 1983; White, 2005). The biopsychosocial model is thought to have several important implications for health treatment, including an increased focus on psychosocial factors within the patient-doctor relationship (Alonso, 2004).

Although Engel's original intent in developing the biopsychosocial model was to reduce a strict emphasis on biomedicine and increase holistic approaches within healthcare, practitioners and researchers have criticized its application within medical and psychiatric training as failing to appropriately integrate biological and psychological facets of health (Alonso, 2004; Hatala, 2012; Tavakoli, 2009). The biopsychosocial model is theoretically congruent with a scientific systems or complexity paradigm (McDaniel et al., 2013); however in practice it is often applied using classical scientific paradigms more closely tied to the biomedical model (Alonso, 2004: Hatala, 2012). Despite theoretical agreement with the philosophy of the biopsychosocial model, medical practitioners cite lack of personal interview skills, time, and training in psychosocial health as major barriers in attending to patient's psychosocial needs (Biderman et al., 2005; Herman, 1989). In other words, medical care providers may often feel unprepared

to contend with the scope of health determinants included in the biopsychosocial model, particularly in relation to psychosocial determinants.

Furthermore, uneven application of the biopsychosocial model within healthcare may also be attributable to lack of specificity within the model itself. Though it supports a more complex concept of health than the biomedical model, the biopsychosocial model fails to provide guidance in the meaningful practice of biopsychosocial health care (Weston, 2005). In this void, physician Wayne Weston (2005) suggests that the medical community have largely approached psychosocial health through familiar practice standards of the biomedical model which includes an emphasis on disease and promotes a power hierarchy of doctor-as-expert. Weston cites this approach as having significant clinical implications in attending to emotional and social health determinants, which are not appropriately conceptualized or treated from a biomedical approach. He further suggests the need for a "patient-centered" approach (e.g., increasing patient-provider dialogue and promoting the value of subjective patient feedback) as a means of course-correcting biopsychosocial application in medical practice. This suggestion may reveal a more significant failure of the biopsychosocial model: a lack of guiding ethic in how patients and care providers contribute to the healthcare process. While healthcare aligned with the biomedical model assumes a clear power hierarchy–e.g., health is defined as the absence of disease, and medical doctors have the expertise to identify and treat disease–a biopsychosocial concept of health includes health factors that cannot be understood without participation of the individual.

Additionally, the biopsychosocial model does not provide an explicit framework for understanding the integration of biological, psychological, and social factors of health. Resultantly, biological and psychosocial factors of health are approached as distinct and nonintegrated constructs, congruent with Cartesian concepts of health, leading to misunderstanding and mismanagement of psychosocial factors. The consequences of a nonintegrated biopsychosocial model are particularly salient in the case of mental health symptomology. Psychiatrist Hamid Tavakoli writes, "The biopsychosocial model, however unintentionally, promotes an artificial distinction between biology and psychology, and this does not help our cause in trying to destigmatize mental health" (2009, pg. 29). Tavakoli further cites that medical providers have utilized the biopsychosocial model in such a way that psychiatric illness is seen as volitional and unconnected to biomedical health, thus increasing the stigma around mental health disorders. These critiques are significant, as mental health disorders are now considered one of the leading causes of disease burden and disability across the globe (Office of Disease Prevention and Health Promotion, 2016).

However, recent shifts in health care have resulted in attention to the biopsychosocial model (Johnson, 2012). In response to past critiques, researchers have suggested further development of the biopsychosocial model in order to improve it's utility in the current health landscape. As discussed by Borrell-Carrió et al. (2004), intellectual trends over the last 25 years have evolved to account for the socially constructed nature of knowledge categories, such as "body" and "mind". The authors suggest that overly literal concepts of biopsychosocial categories, such as psychological

versus biological, will create artificial boundaries between concepts and limit flexible out-of-the-box thinking in understanding the casual relationships between health factors. Hatala (2012) builds upon this concept, and highlights the need for increased integration of health factors utilizing holistic perspectives. According to Hatala, a holistic approach, also described as multi-level integrative analysis, assumes equality and interconnectedness between factors of a whole (2012). The inclusion of holism to the biopsychosocial model is significant. In addition to integrating aspects of health (they are interconnected), a holistic perspective also describes the relationships between health factors (they are equal and form a whole). Hatala (2013) posits an increased focus on holism in biopsychosocial models should provide fewer conceptual barriers in integrating contemporary researcher findings, such as the significant contribute of spiritual dimensions of biopsychosocial health.

Critiques of the biopsychosocial model suggest that increased utilization of holistic perspectives (Hatala, 2012), as well as elements of social constructivism (Borrell-Carrió et al., 2004), may improve the utility of the biopsychosocial model in health research and practice. Similarly, the inclusion of patient feedback as a significant source of health knowledge may prove to be a critical step forward in the meaningful practice of biopsychosocial care (Weston, 2005). Interestingly, an existing health model more closely related to the social sciences—the model of holistic wellbeing—may arguably be described as a holistic, patient-centered biopsychosocial model.

Holistic Wellbeing

Wellness and wellbeing have emerged as significant health related concepts over the last several decades "to describe the 'total person' approach for improving quality of life" (Witmer & Sweeney, 1992, p. 140). Halbert Dunn, author of *High Level Wellness*, was one of the first health writers to describe the concept of wellness, defining it as "an integrated method of functioning which is oriented towards maximizing the potential of which an individual is capable" (Dunn, 1961, p.4). The "wellness movement" has been closely linked to researchers and practitioners building upon the WHO 1948 conceptualization health, highlighting the need for a health model that includes a sense of total wellbeing in multiple life domains (Miller & Foster, 2010). Holistic wellbeing is congruent with the biopsychosocial model utilized in medical science and health psychology; however, models of holistic wellbeing are thought to place more emphasis on the individual (patient-centered) and their agency in pursuing a healthy lifestyle (Swarbrick, 2013). As previously discussed, wellbeing research may be found in a plethora of fields (though commonly in social sciences), and may differ slightly in conceptualization. However, a review of health literature across multiple disciplines highlights three major factors that identify a wellbeing model of health: (a) the presence of holistic philosophy, (b) an emphasis on subjectivity, and (c) the inclusion of positive health factors and coping skills (Diener, 1984; Myers, Sweeney, & Witmer, 2000; Miller & Foster, 2010).

As the study of wellbeing has evolved in the last century, the most common definitions of wellbeing include a holistic perspective that consists of multiple

dimensions (Miller & Foster, 2010). The World Health Organization (2008) recently stated that the dominant understanding of wellbeing should be holistic in scope, and should conceptualize health as more than the absence of illness. As previously discussed, human wellbeing includes dimensions such as the mind (mental consciousness and emotional responses), the body (biological realities), and community (social factors). A holistic perspective does not consistently prioritize factors of wellbeing, but rather views dimensions as interconnected. Holistic models of wellbeing are consistent with complexity paradigms, and prioritize order through fluctuation, continuous diversification, evolution towards complexity, and probalistic descriptions based on ensembles rather than averages (McDaniel et al., 2013).

The inclusion of subjective perspectives is an additional factor in the evolution of research and treatment of wellbeing. Although wellbeing is comprised of various measurable biological and psychosocial factors, the experience of wellbeing will vary according to the individual. *Eudaimonia*, the Greek word from which we derive *wellness*, translates to "flourishing, well-being, or the opportunity to lead a purposeful and meaningful life" (Sirgy, 2012, p.6). Notably, one's assessment of "a meaningful life" may greatly vary in relation to the experience of disease (Cella & Tulsky, 1993). For example, individuals with the same level of illness or disability may vary in their personal assessment of how their disease impacts their life satisfaction. Additionally, emphasis on the subjective experience of wellbeing also contributes to a paradigm shift in how medical care providers understand illness and disability. An increased focus on subjective experience and personal functioning characterizes illness as a spectrum rather

that a discrete category according to how it impacts each individual's daily life (Evers et al., 2015). By definition, assessment of holistic wellbeing is theoretically impossible without collaboration between patients and care providers, assuming an egalitarian hierarchy that contrasts with the biomedical model.

Furthermore, models of wellbeing vary from biomedical or current biopsychosocial models of health in their inclusion of positive factors–which are thought to empower individuals in their pursuit of wellness–as significant determinants of health (Swarbrick, 2013; Miller & Foster, 2010). The World Health Organization (1948) definition of health as more than "the absence of disease and disability" provides theoretical space for how we conceptualize health, but fails to explicitly describe it. Models of holistic wellbeing explicitly define the space beyond "absence of disease" to include the presence of positive health factors. Wellbeing is not a static construct, such as a disease state, but may be considered an outcome as well as a process towards optimum health (Myers & Sweeney, 2005a). Wellbeing can be increased through intervention (Adamsen et al.,2006; Velikova et al., 2004), and is aimed at improving quality of life (Miller & Foster, 2010; Swarbrick, 2013) and disease prevention (Witmer & Sweeney, 1992).

As discussed, the biomedical model does not appropriately meet the current population health needs (Armentrout, 1993; McGrady & Moss, 2013; McWhinney, 1986). Though the biopsychosocial model is considered the prominent alternative health model (Johnson, 2012), it does not define the relationships between biological, psychological, and social determinants of health (Alonso, 2004; Hatala, 2012; Tavakoli,

2009) and fails to clearly identify how biopsychosocial health care may be accomplished. In these gaps, practice standards and concepts of health borrowed from the biomedical model have been substituted (Alonso, 2004; Weston, 2005). Conversely, models of holistic wellbeing inherently include guidelines for practice to include subjective, patient-centered approaches and utilize a wide spectrum of health determinants (positive and negative) in care planning. Whereas the biopsychosocial model provides a strong foundation for the future of health conceptualization, holistic wellbeing builds upon biopsychosocial models to include a path forward.

The adequate practice of a biopsychosocial concept of health, particularly a holistic wellbeing perspective, includes the recognition, assessment, and treatment of a wide spectrum of health determinants. Quite reasonably, fulfilling the scope of these needs is impossible for biomedical care providers alone. As previously discussed, a substantial number of physicians have cited theoretical agreement with a biopsychosocial concept of health, but are not trained to provide total biopsychosocial care (Biderman et al., 2005; Herman, 1989; Weston, 2005). The use of interdisciplinary provider teams, including mental health experts, is needed to accomplish holistic care (Johnson, 2012). In response to these needs, the last few decades have seen the emergence of a new model of healthcare delivery known as integrated models of care.

Integrated Models of Care

The rise in chronic and lifestyle related illness across the globe has led to significant challenges in the health care system. As McGrady and Moss (2013) point out in *Pathways to Illness, Pathways to Health*, "It is becoming increasingly clear that

optimal therapeutic approaches for people with chronic emotional and physical problems must be comprehensive, integrative, and carefully individualized" (2013, p. *v*). In an attempt to improve integration between health organizations and levels of care to meet complex population health needs, integrated models of care have emerged (Evans, Baker, Berta, & Barnsley, 2013).

Whereas the biomedical model and biopsychosocial models of health describe the nature of health, models of health care describe how health treatment should be delivered within health organizational systems. Integrated models of care, or integrative medicine, are "a comprehensive and holistic approach to health care in which all health care professionals work collaboratively, in an equal and respective manner, to better meet the needs of the patient and community" (Leach, 2006, p.1). Integrated models of health care can include a diverse group of disciplines and practitioners (e.g., physicians, nurses, psychologists, mental health counselors), and are characterized by the sharing of patient care-related information between coordinating professionals in order to establish a comprehensive treatment plan to address holistic biopsychosocial needs (American Psychological Association, 2016). Primary care plays a critical role in integrated health care, and is considered the entry point into specialized health services. Primary care providers ideally provide long-term care to patients, maintain a close doctor-patient relationship with patients and their families, and serve as knowledgeable gatekeepers to the broader health care system (Hawk, 2002).

Similar to complex health models, such as holistic wellbeing, integrated care involves significant shifts in practice and the application of complex paradigms. The

2013 *Annual Review of Health Care Management* provides an in-depth review of integration health care literature from the past 25 years that reveals several core aims of the integrated health care movement, as well as future directions of health integration (Evans et al., 2013). Integrated care models require a shift in focus from institution-centered models to a broader focus on community-based health and social services. The shift often requires individual institutions to prioritize a patient-centered approach, which may often include collaboration with community partners for specialized services (such as case management or mental health counseling). Furthermore quality care, as opposed to economic arguments, must serve as the primary ethics (Evans et al., 2013).

It is also significant to note that shifts in emphasis of health care do not imply that previous models consistent with biomedical health care will be entirely obsolete, nor that biomedical strategies will not be implemented (Evans et al., 2013). The biomedical model and holistic biopsychosocial models are distinct in focus, but are not mutually exclusive. Wellness approaches to integrative medicine may prove particularly complimentary to integrating biomedical and biopsychosocial perspectives (Swarbrick, 2013). Dr. Swarbrick, advocate of wellness-integrated care in occupation therapy, writes:

> Whereas the medical model focuses on symptom reduction, the wellness model and [wellness practitioners] focus on wellness and consider the goals, values, preferences, interests, and strengths of the individual. The wellness approach is multidimensional, whereas the medical model tends to focus on illness, symptoms, deficiencies, and incapacity. The wellness approach emphasizes the importance of individuals assuming responsibility to help (re)establish roles and pursue health and wellness goals, whereas the medical model places more emphasis on medication or other treatments to eliminate or reduce symptoms or discomfort (2013, p. 275).

Notably, there exist significant challenges to utilizing integrated models of care into current health systems. The current healthcare system is fragmented into a series of specialty health professions that, once considered innovative, realistically serve to partition dimensions of health care and promote inefficiency, ineffectiveness, and confusion for individuals seeking health treatments (Stange, 2009). Integrated models of care require multidisciplinary collaboration, rather than disciplinary competition– a concept many health specialists may eschew (Evans et al., 2013). Integrative health care goes beyond adding therapies to a treatment regime, but often includes openness to perspectives from a dissimilar health discipline (Leach, 2006). Healthcare stakeholders who promote the commoditization and commercialization of health care (notably specialist drug and device makers, and hospital and service business agencies) are primarily concerned with reimbursement for services, and may act as a significant barrier in organizing integrated patient-centered health care systems (Evans et al., 2013; Stange, 2009).

Regardless of these challenges, integrated models of care are needed to respond to increasing gaps in population health, most notably psychosocial health factors that contribute to chronic health difficulties. Fortunately, the passage of the Affordable Care Act in the US has sparked movements in health care systems and service delivery that are expected to be increasingly inclusive of psychosocial health care, particularly mental health, within an integrated health framework (Swarbrick, 2013). Biopsychosocial models of health care are considered the future paradigm of integrated health fields (Johnson, 2012; Leach 2006), and will require an increased effort to approach health as a

holistic concept (Hatala 2012; McGrady & Moss, 2013). The emerging paradigm shift within Western medicine will provide significant opportunities for psychosocial health professionals, namely counselors, psychologists, and social workers, to fill current gaps in care and to provide critical perspectives in improving psychosocial treatment within an integrated biopsychosocial health paradigm.

Holistic Wellbeing: Cancer Related Effects

As previously discussed, cancer is among the leading global health concerns (Centers for Disease Control and Prevention, 2016b), and is expected to impact a sizeable proportion of the global population. Currently, approximately one-in-two men and one-in-three women in the United States can expect a diagnosis of cancer in their lifetime (American Cancer Society, 2017). Cancer is known to impact personal wellbeing on multiple dimensions, and across multiple time points, in the cancer journey (e.g., Landmark, Strandmark, & Wahl, 2001; Pearman, 2003; Sim, Lee, Kim, & Kim, 2015). Interventions aimed at improving wellbeing should take into account the multiple, integrated factors that effect and comprise holistic health. Additionally, recognition of findings from multiple health fields may be useful in approaching health disparities in an integrated health framework. This section will provide a brief review of known effects of cancer on holistic wellbeing among cancer survivors. Significant effects and factors are outlined throughout oncology research literature, which has been generated from a range of disciplines that include medical, pharmaceutical, nursing, social work, psychiatry, psychology, and counseling literature. Significant factors and effects include those that have a significant negative or positive impact on holistic wellbeing during the cancer

experience. Similarly, this section will highlight findings from multiple researcher fields that underscore the importance of mental health to holistic wellbeing in cancer survivors.

Emotional Wellbeing

Emotional wellbeing may be conceptualized as a continual process that incorporates the awareness, constructive expression, and management of emotions (Hettler, 1980). A general review of emotional wellbeing found consistent definitions of emotional wellbeing as an awareness and control of feelings, which includes a positive and developmental view of conflict, life circumstances, and the self (Roscoe, 2009). Emotional wellness is not predicated by the presence or absence of negative emotion, but rather the ability to cope with negative emotions (Myers & Sweeney, 2005a; Roscoe, 2009). Emotional wellbeing is influenced by multiple psychosocial factors including social relationships, existential/spiritual philosophy, functional ability, and coping strategies (Torta & Ieraci, 2013).

Cancer, regardless of the outcome, is thought to contribute to the psychological adjustment of the individual (Rolland, 2005). As has been illustrated in the previous sections, cancer impacts emotional wellbeing on multiple fronts. For example, functional losses from cancer (e.g., Livneh & Antonak, 2005; Yabroff, Lawrence, Clauser, Davis, & Brown, 2004), cancer impact on social support structures (e.g., Boerger-Knowles & Ridley, 2014), and cancer-related existential crises (Kandasamy, Chartuvedi, & Desai 2011) are all known to significantly impact and predict emotional wellbeing and the presence of mental health symptomology.

Psychological outcomes of cancer-related adjustment have been increasingly examined over the last few decades. More commonly, negative emotional variables such as common mental health disorders (e.g., depression and anxiety) have been examined. The following section provides a brief review of researcher findings related to cancer survivorship and negative mental health effects.

Mental health disorders. Mental health issues such as depression, anxiety, post-traumatic stress disorder (PTSD), grief, and other mood disorders have been shown to have a significant relationship with the experience of having cancer (e.g., Honda & Goodwin, 2004; Massie, 2004; Miovic & Block 2007; Nakash et al., 2014). Co-occurring mental health difficulties within the cancer experience have been shown to vary according to level of disability, illness advancement, and pain (Kroenke et al., 2010; Meyerowitz, 1980). Earlier studies indicate that around 50% of newly diagnosed cancer patients meet the criteria for a psychiatric disorder, with symptoms of depression and anxiety being the most common (Derogatis et al. 1983).

Depression may be considered the most prevalent and well-documented of these disorders, as researchers have indicated that 20-30% of cancer patients will experience significant depressive symptomology during the course of their cancer experience (Honda & Goodwin, 2004; Irwin et al., 2014). Depression rates are expected to vary according to cancer type and prognosis, with higher rates of depression among pancreatic, breast, and lung cancers (up to approximately 45% across cases), and lower rates of depression with cancers such as colon, gynecological, and lymphoma (Massie, 2004). However, studies that attempt to measure specific mental health comorbidity have been criticized for their

lack of diagnostic criteria in measuring mental health symptoms and range of mental health expertise among researchers (Walker et al., 2013). Some researchers suggest there may be a significant gap between true and treated prevalence rates of psychiatric disorders, with higher projected rates of mental health disparities across all populations (Kessler et al., 2009; Nakash et al., 2014).

Furthermore, research examining the relationship between cancer and mental health symptoms, particularly depression, is nascent. Depressive disorders are highly correlated with chronic illnesses generally, which may be attributable to "depressive disorders precipitating chronic disease and to chronic disease exacerbating symptoms of depression (Chapman, Perry, & Strine, 2005)." The relationship between depression and chronic illnesses such as cancer has been linked to biological, behavioral, and psychological pathways. Biologically, psychological distress and depression contribute to immune dysfunction related to the onset and outcome of certain types of cancer (Currier & Nemeroff, 2014; Reiche, Morimoto, & Nunes, 2005). Though modest researcher findings support the hypothesis that depression is related to cancer onset or incidence (e.g., Kroenke et al., 2005), medical researchers have largely established that depression has negative impact on biological factors associated with cancer progression (Currier & Nemeroff, 2014; Moreno-Smith et al., 2010; Reiche et al., 2005). Behaviorally, depression is thought to contribute to a reduction in positive health behaviors, most notably reduced treatment adherence and utilization of oncological resources (Fresche de Souza et al., 2014; Nakash et al., 2014). This non-adherence may potentially threaten a patient's health, and may lead to diminished healthcare outcomes. Psychological

symptoms of depression, which include lack of motivation, feelings of worthlessness, reduced cognitive processing, and social withdrawal (American Psychiatric Association, 2016), are thought to mediate patient non-adherence (DiMatteo & Haskard-Zolnierek, 2011).

Mental health challenges may also vary according to stages in the cancer journey. The timing of co-occurring mental health disorder onset varies, but cancer survivors in active status treatment show higher levels of mental health difficulties than both recently diagnosed patients and cancer survivors in full remission (Nakash et al., 2014). Newly diagnosed cancer survivors experience a whirlwind of emotional stressors from the moment they receive their diagnosis, including fears of the future and emotional shock (Houldin, 2000). Common emotional stressors for patients undergoing cancer treatment may include difficult emotions experienced in relation to getting cancer (e.g., existential concerns), concerns about the impact of their cancer on their families and friends, coping with the intensity of cancer symptoms and treatments, body image issues, and resultant loss of control over daily activities and abilities (Houldin, 2000). Post-treatment cancer survivors, in addition to adjusting to post-cancer life changes, are known to significantly experience fears of reoccurrence that have been associated with higher distress and mental health difficulties such as increased anxiety and depressive symptoms (Deimling, 2006).

Although cancer has been shown to contribute to negative mental health outcomes, cancer may be viewed like any major psychosocial transition and has the potential for both positive *and* negative outcomes (e.g., Balfe et al., 2016; Bekteshi &

Kayser, 2013; Cordova, Cunningham, Carlson, & Andrykowski, 2001). In recent years, the proliferation of negative outcome based studies on cancer-related psychological adjustment has been criticized as being unrepresentative of the cancer experience (Adler et al., 2008). Furthermore, some positive factors that affect holistic wellbeing are protective against negative factors; for example, positive social support is known to reduce intensity of depressive symptoms among cancer survivors (Applebaum et al., 2014). Though comparably scarce, emerging research has shown an increase focus on positive psychological outcomes (Costa, Mercieca-Bebber, Rutherford, Gabb, & King, 2016), most notably post-traumatic growth (PTG) (Costa et al., 2016; Shand, Cowlishaw, Brooker, Burney, and Ricciardelli, 2015).

Posttraumatic growth. Posttraumatic growth is a widely known concept that refers to the "positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (Tedeschi & Calhoun, 2004, p. 1). In the process of PTG, an individual's way of understanding the world in changed due to a traumatic event, and engagement with significant psychological distress of the traumatic event often leads to person and productive growth (Calhoun & Tedeschi, 1999). While cancer is known to be a highly stressful and traumatic event (Butler, Koopman, Classen, Spiegel, 1999; Kangas, 2013), individuals may respond differently to cancer related distress. Reports of positive change and growth as a result of the cancer experience have been increasingly cited across multiple fields of oncological literature (e.g., Balfe et al., 2016; Connerty & Knott, 2013; Wilson, Morris, & Chambers, 2014).

Similar to negative mental health outcomes, positive mental health outcomes such as PTG are the result of several complex psychosocial factors (Connerty & Knott, 2013). Positive factors of emotional wellbeing, including optimism, spirituality, and positive coping styles are strongly correlated with PTG (Shand et al., 2015). Qualitative studies exploring PTG factors among cancer survivors found that supportive relationships, maintaining preventative health behaviors, and lifestyle changes aimed at improving existential meaning significantly contributed to PTG (Connerty & Knott, 2013). A 2015 study on PTG among stomach cancer survivors (Sim et al., 2015), found that over half of all participants (53.6%) experienced moderate to high levels of PTG. It was also found that higher levels of social and financial wellbeing were significantly tied to higher rates of PTG, while older age, lack of religion, and lower socio-economic status were tied to lower levels of PTG. Financial difficulties have been found to be significant with both high and low levels of PTG (Balfe et al., 2016; Ho et al, 2011). High levels of social support during the cancer experience has been positively associated with posttraumatic growth among various types of cancer patients, including head and neck (Balfe et al., 2016), breast (Lelorain, Tessier, Florin, & Bonnaud-Antignac, 2012), and prostate cancers (Wilson et al., 2014). Cancer survivors experiencing PTG may also experience depression, PTSD or anxiety (Shand et al., 2015); however PTG may provide a buffering effect of negative cancer-related outcomes (Connerty & Knott, 2013).

Based upon current research findings and recommendations, appropriate assessment of emotional wellbeing of cancer survivors should include a broad range of psychosocial factors (Lai, Garcia, Salsman, Rosenbloom, & Cella 2012; Shand et al.,

2015). It has been suggested that broad assessment of psychosocial factors may be as beneficial in supporting PTG as it is in determining risk for mental health difficulties (Connerty & Knott, 2013). Emotional wellbeing of cancer survivors should also be understood in relation to physical wellbeing, as the relationship between physical and emotional health in cancer survivors is inextricably intertwined (Shapiro et al., 2001).

Physical Wellbeing

Physical wellbeing may be understood as "the active and continuous effort to maintain the optimum level of physical activity and focus on nutrition, as well as self-care and maintaining healthy lifestyle choices" (Roscoe, 2009, p. 219). Traditionally, concepts of physical wellbeing are closely tied to biological health. Conceptualizations of physical wellbeing are often defined by maintenance of fundamental biological systems, such as the maintenance and improvement of strength, fitness, and cardiovascular health (Hettler, 1980; Leafgren, 1990). Notably, concepts of physical wellbeing commonly presume ideal physical functioning as a reasonable outcome in the measurement or pursuit of physical wellbeing. This presumption is ill-suited for conceptualizing the wellbeing needs of individuals with physical limitations, such as the disabled or medically ill. In her definition of physical wellbeing, Roscoe (2009) suggests the inclusion of "acceptance of one's physical state" as a necessary component. This definition, she argues, allows individuals to move towards a personally defined optimal state of physical wellbeing, allowing for variation of physical wellbeing according to circumstance.

A definition of physical wellbeing that includes subjective variation according to personal ability is particularly appropriate in conceptualizing the physical wellbeing of cancer survivors. The experience of cancer has been related to multiple effects on physical health, and includes physical effects from specific cancer disease types as well as treatment related effects (Falvo, 2005). Cancer types vary according to tissue type from which they originate (e.g., leukemia is cancer of the blood) and cancer stage (e.g., the extent to which cells have spread in the body) (Falvo, 2005; National Cancer Institute, 2015). Direct physical effects of cancer also vary by type, but commonly include chronic and/or acute pain at the cancer site (World Health Organization, 1996). Worldwide prevalence rates of acute or chronic pain among cancer survivors include 64% of patients with metastatic or terminal disease stage cancer, 59% of patients receiving anticancer treatment, and 33% of patients who are considered cancer-free (Everdingen et al., 2007). Cancer related pain has been linked to emotional distress (Ogbeide & Fitch-Martin, 2016) and is thought to negatively impact quality of life (Green, Hart-Johnson & Loeffler, 2011).

Cancer treatments, whether singular or combined, are intended to cure cancer, prevent metastasis, or extend life (Falvo, 2005); however, common forms of cancer treatment such as chemotherapy, radiation, and surgery, are also known to negatively impact physical wellbeing. Chemotherapy includes a variety of chemical agents intended to destroy cancer cells. In many cases, chemotherapy treatments also damage normal cells that regulate multiple bodily functions. Common physical effects of chemotherapy include significant fatigue, anemia, nausea and vomiting, weight changes, nerve and

muscle problems, changes in libido, cognitive impairment (chemo brain), and changes in mood (American Cancer Society, 2016; Adler et al., 2008). Radiation therapy includes high energy rays used to damage cancer cells, and is applied to targeted areas of the body. Common effects of radiation include fatigue, nausea, skin irritation and pain, headache, and vomiting. Some of these side effects may occur immediately, or months after radiation has been administered (Falvo, 2005). Radiation is also associated with long-term side effects including permanent bodily damage to radiation area, as well as increased risk for a secondary cancer occurrence (American Cancer Society, 2015). Some treatment related effects include permanent changes to physical functioning (Adler et al., 2008). An example of such a treatment would include surgical interventions, which comprise the surgical removal of cancer tumors, infected tissues, or preventative removal or tissue high-risk areas of the body (e.g., mastectomy). Surgical side effects include pain and impairment (e.g., lengthy discomfort at surgical site) or permanent disfigurement (Falvo, 2005).

Physical decline related to cancer and its resultant treatments has been linked to significant mental health comorbidity among cancer survivors (Fresche de Souza et al., 2014; Mansoor, & Jehangir, 2015; Nakash et al., 2014). Chemotherapy and radiation treatment, which are associated with longer treatment times, loss of functional status, and increased hospitalizations, have been significantly linked with anxiety and depression (Jacobsen & Jim, 2008; Mansoor, & Jehangir, 2015). Researcher findings suggest that co-occurring mental health difficulties, such as depressive symptoms, may impact the long-term effectiveness of radiation treatment (Heyda et al., 2015). Co-occurring mental health

difficulties among cancer survivors receiving treatment also has been linked to decreased treatment adherence (Fresche de Souza et al., 2014; Barre et al., 2015). A 2014 study (Fresche de Souza et al.,) on the impact of depression on treatment adherence among breast cancer survivors found that patients who endorsed depressive symptoms during chemotherapy treatment displayed higher levels of treatment non-compliance than those with no depressive symptoms. This is problematic, as reduced treatment adherence may lead to further disease impact and increased mortality risk (Adler et al., 2008; Nakash et al., 2014). Additionally, adults with cancer or a history of cancer more frequently report poorer health as evidenced by increased types of other chronic conditions (42%), limitations in the ability to perform daily activities (11%), and other functional disabilities (58%) (Hewitt, Rowland, & Yancik, 2003). This leads to another critical area: functional wellbeing.

Functional Wellbeing

Functional wellbeing may be considered "the ability of a person to perform the usual tasks of daily living and to carry out social roles." (Australian Institute of Health and Welfare, n.d., para. 1). Functional wellbeing is often closely tied with physical wellbeing, as it is directly impacted by one's physical health. Cancer survivors are known to commonly experience a decrease in functional wellbeing, largely due to the negative physical effects of cancer and cancer related treatments (Adler et al., 2008). For example, treatment side effects such as chest radiation may occasionally result in damaged lung function, consequently impacting an individual's previously held ability to engage in work or leisure activities (American Cancer Society, 2015). Adults with a

history of cancer, compared to a cohort of adults with no cancer history, are more likely to require help with daily tasks of living (Yabroff et al., 2004). These tasks, such as bathing, dressing, preparing meals, and feeding oneself may become extremely difficult or impossible, depending on cancer type and treatment (Adler et al., 2008).

Cancer-related physical changes, whether temporary or permanent according to cancer type and treatment, may significantly affect one's ability to engage in vocational roles. Vocational roles are known to significantly contribute to one's sense of emotional wellbeing, but are also dependent on retaining personal health (Carr et al., 2003; Livneh & Antonak, 2005). A 2008 study (Short, Vasey, & BeLue) on cancer survivors found that 27% of males and 32% of females experienced cancer-related work disability. Work disability rates tended to decrease as length-of-time in remission increased. The authors cited study limitations of their sample, which had high SES and educational backgrounds, and suggest that true cancer-related work disability rates may be higher in the general population. Similarly, risks related to relapsing and remitting courses of cancer, such as several cases of non-Hodgkin's lymphoma, may significantly affect one's ability to maintain employment or plan for the future (Bellizzi et al., 2007).

Changes in individual functional wellbeing, as well as the steep cost of cancer treatments, may often contribute to adverse effects on economic wellbeing of the individual and the family. The 2006 National Survey of U.S. Households affected by cancer found that 25% of families who had experienced the impact of cancer in the last 5 years were significantly struggling with finances, with 10% of all participants reporting they were unable to pay for basic necessities including utilities, food, and housing and

3% of the same participants reporting needing to declare bankruptcy (*USA Today*, Henry J. Kaiser Family Foundation, & Harvard School of Public Health, 2006). In a 2007 study exploring the positive and negative life changes experienced by survivors of Non-Hodgkin's Lymphoma, researchers found that the most negative life change reported was survivors' financial difficulties (Bellizzi et al., 2007). Financial difficulties have been shown to have a direct negative impact on quality of life among cancer survivors (Hamilton et al., 2013), particularly in terms of psychological adjustment (Sharp, Carsin, & Timmons, 2013), and are also thought to cause distress among caretakers of cancer survivors (Balfe et al., 2016). While the physical side effects of cancer significantly impact individual functional wellbeing, the financial impact of cancer may significantly alter the functional wellbeing of the entire family unit. Functional changes in the individual and family unit have also been linked to significant effects on social wellbeing (Rolland, 2005).

Social Wellbeing

Social wellbeing is a critical factor in holistic wellbeing, and includes both public and private domains. Social wellbeing may be defined as the appraisal of one's circumstances and functioning within society (Keyes, 1998). Social wellbeing may be understood through multiple dimensions, including one's sense of being integrated into society, one's sense of contribution to society, and one's sense of connectivity to closer social spheres such as family and friends (Keyes, 1998; Roscoe, 2009).

Cancer is known to have significant affects on both personal and private domains of social wellbeing. Cancer may often feel isolating or stigmatizing for the cancer

survivor (Macmillan Cancer Support, 2013), and this sense of isolation can create significant relational shifts (Boerger-Knowles & Ridley, 2014). Researchers have noted the phenomenon of social stigma as a significant experience among cancer survivors, with varying sources of stigma among different cancer types. For example, in a qualitative study of psychosocial needs among lung cancer survivors, results from 21 in-depth interviews highlighted social stigma as a prevalent psychosocial effect of having lung cancer (Rohan, Boehm, Allen, & Poehlman, 2016). The researchers reported themes of stigma among participants, which included feeling blamed for having cancer, feeling stigmatized as "throwaways" among other cancer survivor types, and feeling surprised and unsure about their survival (Rohan et al., 2016), as lung cancer is considered to be the most deadly type (American Cancer Society, 2017). A 2009 study (Else-Quest, LoConte, Schiller, & Hyde) of the experience of stigma among lung, breast, and prostate cancer patients revealed significant levels of self-endorsed stigma among all cancer types, with lung cancer being the highest, as well as a positive relationship between perceived stigma and poor psychological adjustment. Cancer related social stigma has a variety of larger effects on multiple cancer types, including but not limited to changes in interactions with acquaintances, family, friends, and health care providers, as well as decreased utilization of support services (Chapple, Ziebland, & McPherson, 2004; Else-Quest et al., 2009). Furthermore, the effects of social stigma during the cancer experience have been linked to the experience of significant mental health difficulties, including the onset of depression or anxiety (Brown Johnson, Brodsky, & Cataldo, 2014; Phelan et al., 2013).

Social support is thought to be a protective factor against negative cancer related health outcomes, and may decrease mortality risk (Weihs, Enright, & Simmens, 2008). However, perceived social support may be more critical than actual support available or received (Wethington & Kessler, 1986). Cancer survivors range in their utilization and existing sources of social support. A recent UK report publishing results from a national sample found that 8% of male cancer survivors and 6% of female cancer survivors reported having zero sources of social support during their cancer experience (Macmillan Cancer Support, 2013). Though these numbers may realistically include individuals who fail to utilize social support, as well as those without access to social support, the implications of social isolation during the cancer experience are significant.

Alarmingly, biological researchers have found that individuals who are socially isolated during the cancer experience, regardless of whether by choice or circumstance, may have increased disease burden and exacerbated tumor growth (Hermes et al., 2009). Low social support has been linked to negative mental and physical health outcomes, including higher rates of depressive symptoms (Burgess, 2005) and higher levels inflammation and pain (Hughes et al., 2014). Conversely, researchers have affirmed that higher levels of social support are associated with decreased symptoms of anxiety and depression (Applebaum et al., 2014; Dour et al., 2014) and improved psychological adjustment (Wethington & Kessler, 1986; Lien, Lin, Kuo, & Chen 2009). Social support has also been shown to positively influence health behaviors in cancer survivors, as social supports are thought to enhance motivation to engage in positive health behaviors such as choosing a healthful diet and engaging in regular exercise habits (Harper et al., 2007).

Cancer is also known to have a significant impact on intimate social structures such as familial relationships. The cancer experience often requires continual adaptation by both the individual as well as their families, which can sometimes lead to distress within the family system (Rolland, 1994). Families are often unprepared for impact of significant diseases such as cancer, and the effects of cancer on social wellbeing are varied, dynamic, and unfold over time. For example, the initial shock of an individual receiving a cancer diagnosis may include emotional volatility, sudden changes in family roles, and immediate practical changes in daily routines (Rolland, 2005). Effects from the course of illness, such as physical disfigurement (e.g., mastectomies in breast cancer), changes in reproductive abilities (e.g., surgical interventions for uterine cancer), and chronic states of illness crises (e.g., episodic leukemia), may create significant losses that must be absorbed by the entire family unit (Livneh & Antonak, 2005; Rolland, 2005). Regardless of outcome, the extent to which cancer alters quality of life or shortens an individual's life span has a profound psychological impact on the family unit (Rolland, 2005).

Although less explored, cancer may also contribute to positive changes in social wellbeing. Among the various positive and negative changes experienced as a result of having cancer, relational growth is among the most common positive change reported by cancer survivors (Bellizzi et al., 2007). A 2013 (Bekteshi & Kayser) qualitative study (*n* = 29) exploring relational growth among mothers with cancer and their daughters found that the majority of mother-daughter pairings (89.65%) reported positive relational growth as a result of the cancer experience. The authors cite factors of authenticity,

mutual support, and empowerment as significant factors facilitating relational growth among mother-daughter pairings. Although the sample was fairly homogenous (majority white, middle class), the authors highlight the significance of relational dynamics in transforming a life-threatening illness into an experience of personal and relational growth (Bekteshi & Kayser, 2013). An additional qualitative study exploring the lived experiences of head-and-neck cancer survivors found that individuals who reported receipt of social support during the cancer experience additionally reported relational growth that included deepened sense of connection and increased gratitude of significant social relationships (Threader & McCormack, 2016). While the authors contend that social support is not solely predictive of positive coping and PTG, social support was found to be particularly salient in finding meaning in the cancer experience. The authors suggest that distressing experiences may be interpreted as a catalyst for illuminating significant relational bonds (Threader & McCormack, 2016). While highlighting the significance of social wellbeing, these findings also underscore the significance of meaning making and existential wellbeing during the cancer journey.

Spiritual and Existential Wellbeing

Existential issues, which affect wellbeing, refer to a spectrum of concerns that come up for individuals when they confront their own mortality and purpose in life (Lee, 2008). Existential concerns are known to be particularly salient for individuals diagnosed with cancer and throughout the entire cancer experience (Breitbart, Gibson, Poppito, & Berg, 2004; Landmark et al., 2001; Morita et al., 2004). Often, a diagnosis of cancer is connected to a "search for meaning". This search for meaning is a normal yet often

psychologically taxing process of determining the impact of cancer on one's life and one's understanding of the world (Lee, Cohen, Edgar, Laizner, & Gagnon, 2004). One's sense of global meaning, a subjective life schema built upon a set of personal beliefs which provide a sense of order and purpose in life, is a key factor in predicting overall wellbeing or quality of life among individuals with cancer (Lee, 2008; Park & Folkman, 1997).

Cancer may challenge one's sense of existential wellbeing in many ways. Belief systems which once provided a sense of security and familiarity, such as religious affiliations or general life philosophies, may be called into question (Lee, 2008). The psychosocial aspects of dealing with a life-threatening illness often involve existential crisis, which includes spiritual and religious domains. Some have even called illness a "psychospiritual crisis" (Kass, Friedman, Leserman, Zuttermeister, & Benson, 1991). One's sense of purpose, connection to a higher power, or comfort with mortality may play a critical role in one's desire to pursue a healthy and holistic life.

Additionally, spiritual/existential wellbeing is linked significantly to emotional wellbeing among cancer survivors. A 2011 study (Kandasamy et al.) on the effects of spiritual wellbeing among advanced cancer patients found that spiritual wellbeing was positively correlated will all aspects of holistic wellbeing, or QoL, and was a significant buffering factor of psychological symptoms of anxiety and depression. The study included fifty patients with advanced illness receiving hospice care, and included a wide range of cancer types. Notably, the significance of spiritual wellbeing and psychological symptoms are less generalizable to all cancer survivors due to the advanced illness status

of the sample. A 2009 study (Nelson et al.) in behavioral medicine exploring the relationship between spirituality and depression among active status prostate cancer survivors found that spirituality was significantly predictive of depressive symptoms, with higher levels of spirituality being inversely related to depressive symptomology. The study included 367 cancer patients, with 45% in early stages of disease, and 55% in later stages of disease. Additionally, the authors noted weaker associations between religiosity and depression, and stronger associations between peace and meaning making with buffering effects on depression (Nelson et al., 2009). These results are more generalizable than the previous study, and also highlight the significance of personal meaning making in emotional wellbeing during the cancer experience.

Conversely, individuals who successfully complete the process of searching for meaning during the cancer journey may experience personal growth, increased personal awareness, increased compassion towards the self, others, and nature, and renewal in their sense of life purpose (Lee et al., 2004; Taylor, 2000). Existential wellbeing is significantly influenced by other aspects of wellbeing, including family support and personal coping strategies (Blinderman & Cherny, 2005).

This section provided a brief review of known factors affecting the holistic wellbeing of cancer survivors, and attempted to emphasize the integration of these factors both generally and in relation to negative mental health outcomes, supporting the holistic interconnected nature of wellbeing. The research presented was generated across several disciplines, and over the last few decades. Despite findings that highlight the salience of psychosocial factors related to the cancer experience, it is widely accepted that treatment

and support for psychosocial wellbeing is lacking (Adler et al., 2008; Chambers et al., 2014; Grassi & Riba, 2014; Holland et al., 2011). The following section will review these gaps, as well as recommendations for improving the state of integrated psychosocial care for cancer survivors.

Psychosocial Care of Cancer Survivors

In 2008, the Committee on Psychosocial Services to Cancer Patients/Families in Community Settings published a comprehensive, 429-page report addressing the state of oncological psychosocial care entitled *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* (Adler et al., 2008). The comprehensive report was produced in collaboration with The National Academies Institute of Medicine in response to a multitude of data suggesting the need for improved psychosocial care for cancer survivors. Although other such projects have been attempted, most notably the brief report from the American Psychosocial Oncological Society, "The IPOS New International Standard of Quality Cancer Care" (Holland et al., 2011), the 2008 report provides the most current and comprehensive report addressing gaps and recommendations for oncological psychosocial care, and will be used as the major framework in outline the purposes of the current study (Adler et al., 2008).

Gaps in Psychosocial Care

In line with other research findings (Houldin, 2000; Nekolaichuk, Turner, Collie, Cumming, & Stevenson, 2013), the 2008 report highlighted the existence of significant gaps in the receipt of psychosocial care among cancer survivors:

> Numerous cancer survivors and their caregivers report that cancer care providers did not understand their psychosocial needs, failed to recognize and adequately address depression and other symptoms of stress, were unaware of or did not refer them to available resources, and generally did not consider psychosocial support to be an integral part of quality cancer care (Adler et al., 2008; pg. 23).

These findings were largely supported by the 2003 and 2004 President's Cancer Panel, which included multiple panel meetings across the nation that invited feedback from cancer survivors of all ages (National Cancer Institute, 2004, pg. 27). Additionally, more recent studies support similar findings. In 2013 study, researchers found that over half of all cancer survivors (55%) report having no discussion with their oncologists about their psychosocial and mental health needs (Forsythe et al., 2013), despite recommended standards of care prompting providers to initiate these discussions as routine oncological treatment (Adler et al, 2008; Holland et al., 2011). A 2014 study measuring comorbidity of mental health disorders found that the majority of patients seeking psychosocial support services from their oncological or primary care physician were not provided additional referrals for mental health needs (Nakash et al., 2014).

These findings are problematic, as oncologists and primary care providers are the gateway to integrated psychosocial services for cancer survivors (Adler et al., 2008; Gilbody, Whitty, Grimshaw, & Thomas, 2003; Hawk, 2002; Miovic & Block, 2007). The authors suggests several factors that contribute to this gap, including low rates of psychosocial screening within cancer programs, a lack of training among oncologists and nurses to detect psychosocial distress, limitations in time allotted for patients visits, and lack of psychosocial professionals within cancer programs (Adler et al., 2008). Additional researcher findings support these claims, including evidence that psychosocial

distress is not easily recognized among medical care providers (Mitchell, Hussain, Grainger, & Symonds, 2011; Mitchell, Rao, & Vaze, 2011; Söllner et al., 2001), resulting in misassessment and lack of needed referrals for psychosocial treatment (Nakash et al., 2014).

Particular gaps have been noted in the lack of attention for mental health symptomology, and failure to close these gaps has been cited as significantly undercutting current medical efforts (Adler et al., 2008). Currently, some billions of dollars are spent on new bio-medical cancer technologies and research, with limited allocation of resources supporting research aimed at closing gaps in psychosocial care. Nancy E. Adler, previous chair to the committee on psychosocial services to cancer patients and families, stated that the failure of medical professions to balance biomedical and psychosocial treatment and research priorities in cancer care is akin to "spending all one's money on the latest model car and then not having the money left to make the gas run" (Adler, 2008, p. *xii*). Improving patients' holistic wellbeing is a valuable pursuit in its own rite, as the purpose of all health professions is to serve the population with their expertise. However, psychosocially distressed patients also have also been shown to be more costly to the health care system. Researchers have affirmed that cancer patients who experience psychosocial distress are more likely to miss appointments, be less adherent to treatment, and be at an increased risk of the progression or reoccurrence of their disease (Carlson & Bultz, 2003; Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Holland, 1999).

Adler et al. (2008) generated several recommendations for action; more notably changes in standards of care to include provision of psychosocial health services

(*Recommendation 1*; Adler et al., 2008). The authors suggest four steps to this recommendation as follows: 1. Facilitating effective communication between patients and care providers; 2. Identifying each patient's psychosocial health needs; 3. Designing and implementing a plan that links the patient with psychosocial services, coordinates biomedical and psychosocial care, and engages and supports patients in managing their illness and health, and; 4. Systematically following up on, reevaluating, and adjusting plans (Adler et al., 2008).

Findings support that the first step in improving psychosocial needs in cancer survivors is interventions to identify patients with psychosocial health needs. Adler et al. wrote, "However it is not sufficient simply to have effective services; interventions to identify patients with psychosocial health needs and link them to appropriate services is needed as well" (2008). Recommendations to improve communication between patients and oncological and primary care providers are a significant first step in identifying needs and increasing patient access to integrated care services. However, as previously mentioned, there exist several barriers to improved communication around psychosocial needs between providers, including gaps provider training in recognizing psychosocial distress (e.g., Mitchell et al., 2011) and provider resistance to initiating discussions related to non-biomedical health (Forsythe et al., 2013; Söllner et al., 2001). Previous researchers have suggested that medical care providers may avoid questions that directly pertain to emotions for fear of evoking strong emotional reactions in their patients (Fallowfield, Lipkin, & Hall, 1998). Furthermore, changes in health care over the last decade have only contributed to increased challenges in the patient-doctor relationship;

health care providers report lack of time with patients due to additional administrative demands as a major barrier in providing adequate health care (Bendix, 2013).

Although improvements in patient-provider communication regarding psychosocial needs must be made, authors of the 2008 report acknowledge that overcoming these challenges will take time. The authors propose that increased focus on screening tools for assessing psychosocial needs may serve as a more expedient solution to current gaps in care. Notably, multiple sources support the need for brief, feasible screening tools as a part of routine assessment of psychosocial needs in cancer care (e.g., Cella et al., 2003; Holland et el., 2011).

However, there exist arguments about what types of psychosocial assessment tools to utilize. Empirically validated measures of mental health symptoms, such as the Hospital Anxiety and Depression Scale (HADS; 14 items self-report measure) (Snaith & Zigmond, 1993) and the Brief Symptom Inventory (BSI)-18 (Derogatis, 2001), have been commonly utilized in measuring psychosocial needs of cancer survivors (Adler et al., 2008). Nevertheless, though these measures and similar measures are known to briefly assess for significant psychosocial factors related with overall psychological distress, they do not assess for fatigue, pain, or other common biomedical factors related to cancer survivor wellbeing. Problematically, there may be significant overlap between somatic features related to mental health disorders and biomedical cancer symptoms. For example, fatigue is a common symptom of depression (American Psychiatric Association, 2013) as well as cancer (Stone & Minton, 2008), leading to confounding

results in screening tools that exclusively measure for distressing psychological symptoms.

Moreover, it has been suggested that screens should assess a broader range of psychosocial health needs (Adler et al., 2008). A more recent movement in psycho-oncology is the recommendation to screen for psychological distress as a means of routine psychosocial assessment (Holland et al., 2011). However, this approach may in fact discount individuals with alternate psychosocial needs. An individual, for example, with limited social support or who is experiencing existential crisis may or may not experience co-occurring symptoms of clinically significant depression or anxiety. Furthermore, as psychosocial factors such as low social support (e.g., Hughes et al., 2014) and existential/spiritual crisis (e.g., Kandasamy et al., 2011) are known to contribute to negative mental health symptoms among cancer survivors; individuals with psychosocial difficulties that do not constitute as psychologically clinically significant may still benefit from preventative counseling services.

Psychosocial Services

Improved identification of psychosocial needs should ideally result in the improved receipt of psychosocial services. Psychosocial services traditionally include health professionals such as psychologists, psychiatrists, counselors, and social workers (Jacob, 2013; National Alliance on Mental Illness, n.d.). Psychosocial treatments may include case management, psychotropic medications (e.g., anti-depressants), and different types of psychotherapy and counseling (National Alliance on Mental Illness, n.d.). The 2008 report, sponsored by the National Academy of Medicine, describe these

services as *psychosocial health services*, and define them as the following: "…psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral aspects of illness and its consequences so as to promote better health" (Adler et al., 2008, pg. 8).

Though subtle, the NIM report provides a differing conceptualization of psychosocial services, their providers, and their function in health care than is consistent with definitions of psychosocial professionals such as mental health counselors. Though this report and subsequent reports from biomedical professionals have called for the increased presence of psychosocial, particularly mental health providers, in cancer care (Adler et al., 2008, Holland et al., 2011; Grassi & Riba, 2014), it is critical to consider how they view these professionals, and how they plan to integrate mental health providers into integrated medical care. For example, the NIM describes the role of psychosocial providers "to optimize biomedical health care" and "to manage the psychological/behavioral aspects of illness and its consequences" (Adler et al., 2008, p. 8). The authors go on to clarify "…when psychosocial services are proposed as worthy of attention from the health care system, the intended effects on health and health care services should be clear" (Adler et al., 2008). This definition appears to relegate psychosocial needs as secondary to, and in service of, biomedical health function. The report often uses the term sequalea (*n.* an aftereffect of a disease, condition, or injury, a secondary result; Merriam-Webster Dictionary, n.d.), in discussing psychosocial health needs related to cancer and other serious illnesses. While the authors of this landmark

report appear to be dedicated to improving psychosocial care, their stance on the salience of psychosocial needs, treatment, and treatment providers contradicts their aims, and reveals the continued bias towards a biomedical model of health. The report espouses to improve cancer care "for the whole patient", indicative of a biopsychosocial perspective, yet describes the purpose of psychosocial treatment as being in support of biomedical outcomes, rather than justifiable health services in their own regards. This subtle bias, sadly, is present in the bulk of health literature generated in non-psychosocial professions.

Evidence has shown that multidimensional approaches to managing psychosocial needs (e.g., depression), including integrated services from primary *and* mental health providers, are more likely to achieve desired outcomes (Gilbody et al., 2003). In order to increase mental health provider collaboration in integrated care, it may be critical for mental health and other psychosocial providers to consider factors that contribute to continued bias towards a biomedical philosophy. For one, biomedical providers and researchers may be hesitant to legitimize psychosocial services based on a scarcity of "valid" research (Adler et al., 2008). Biomedical research is often based on the classical science paradigm, which prioritizes deterministic, clear findings, whereas social science research rarely utilizes a classical science approach as the "best-fit" paradigm (McDaniel et al., 2013). Social science researchers, particularly mental health counselors, often utilize paradigms that prioritize complexity and holism (McDaniel et al., 2013). Biopsychosocial frameworks of health such as holistic wellbeing, are more closely related to social science researcher approaches, and have been considered the future

paradigm of health care (Hatala, 2012; Hatala 2013; Johnson, 2012; Leach 2006). The fundamental concept of health propagated by biomedicine has been accused of denying decades of empirical findings (Yuill et al., 2010). Social scientists in related psychosocial health fields may play a critical role in advocating for biomedical shifts towards complexity science paradigms (McDaniel et al., 2013).

Additionally, psychosocial providers and social science researchers may benefit from increased involvement in biopsychosocial research. A variety of researchers have affirmed the utility of psychosocial services for medical patients, and there is significant evidence to support that psychotherapeutic interventions are effective in reducing psychosocial distress in cancer survivors (Jacobsen, Donovan, Swaine, & Watson, 2006). Cognitive behavioral therapy (CBT; Beck, 1995) (Boesen et al., 2005; Greer et al., 1992; Moorey et al., 1994), psychotherapy aimed at providing emotional support (Goodwin, 2001; Kissane et al., 2007; Spiegel, Bloom, & Yalom, 1981), and couples and family therapy (Kissane et al., 2006; Manne et al., 2006) have proven to be empirically validated treatments for issues like depression and anxiety among cancer survivors. Still, studies validating psychosocial services may be considered few and far between. Increased generation of research from psychosocial service providers, particularly with the use of complex scientific paradigms such as holism, may help bolster evidence as to the effectiveness of psychosocial services among cancer survivors.

Furthermore, medical care providers may be skeptical of psychosocial care providers training when dealing with concurrent illness related symptoms (Adler et al., 2008), which is a fairly valid critique. Although psychosocial care providers often deal

with individuals in an illness state, there exists limited standards for integrating psychosocial and biomedical needs in most health fields. For example, professional counselors claim wellness, an integrated framework of health that includes biological, mental, emotional, social, and spiritual determinants of health, as their foundational paradigm (Myers, 1992). Despite this, counselor educators have questioned the preparedness of counseling students to practice out of this model, particularly in working with clients dealing with significant health decline (Barden, Conley, & Young, 2013). Additionally, Diamond (2007) explored psychologist's understanding of biopsychosocial aspects of patient pain management found that while psychologists scored well on identifying psychological and behavioral aspects of pain, they scored poorly in areas related to biomedical information. In her study, Diamond went on to conclude that lack of knowledge and/or negative attitudes in attending to biological aspects of biopsychosocial complaints adversely affects patient care (Diamond, 2007). Although robust, holistic biopsychosocial care of cancer survivors will require multidimensional and multidisciplinary approaches, evidence supports that both medical care providers (Forsythe et al., 2013; Mitchell et al., 2011) and psychosocial care providers (Diamond, 2007; Ogbeide & Fitch-Martin, 2016) lack the necessary skills to provide biopsychosocial care. In order to close these gaps, increased training of holistic health models may provide enhanced utility in equipping multidisciplinary care providers to adequately assess integrated biopsychosocial health factors (Barden et al., 2013; Hatala, 2012).

Though a majority of biomedical researchers and practitioners may affirm the need for improved psychosocial care services, their efforts to improve psychosocial care will likely not succeed without the increased participation of psychosocial service providers. The NIS report summarizes their strategy as:

> …put[ting] forth a plan delineating actions that that cancer care providers, health policy makers, educators, health insurers, health plans, researchers, and research sponsors, and consumer advocates should take to better respond to the psychological and social stresses faced by people with cancer, and thereby maximize their health and health care (Adler et al., 2008, p.1).

The outlined strategy fails to mention mental health providers or other psychosocial service providers as significant stakeholders or contributors in improving holistic integrated cancer care. More problematically, this strategy fails to include the most significant stakeholder: the patients themselves.

Researcher Recommendations

A final recommendation of the report suggests a researcher focus on developing "psychosocial screening tools addressing a more comprehensive range of psychological and social stressors that can interfere with the ability of patients and families to manage cancer and its consequences" (Adler et al., p. 334). In addition to these recommendations, there may be significant need to assess psychosocial needs within a holistic biopsychosocial framework, rather than a strictly psychosocial framework. As outlined in the brief review of cancer effects on wellbeing, there exist strong links and overlap between biomedical and psychosocial factors that contribute to holistic wellbeing among cancer survivors. Interestingly, more recent researcher findings on the assessment of

psychosocial wellbeing and outcomes in cancer survivors, such as depression or PTG, indicate common coexistence of negative and positive psychosocial symptoms within similar psychosocial domains (Lai et al., 2012; Shand et al., 2015). These findings suggest that psychosocial wellbeing differs widely from biomedical health, as it cannot be understood from a simple presence-or-absence of negative symptomology model. Failure to assess psychosocial and biomedical wellbeing of cancer survivors in tandem undermines empirical evidence that supports the holistic nature of health, and promoting continued bifurcation of psychological, social, and biological health determinants (Hatala 2012; Tavakoli, 2009).

Notably, biopsychosocial measures are already being utilized in cancer care. Measures of quality of life, a concept closely associated with wellbeing (Miller & Foster, 2010), remain the most widely used biopsychosocial assessment tools in cancer care (King & Hinds, 2012; Lavdaniti & Tsitsis, 2015). Unsurprisingly, many of these measures have been criticized for their bias towards biological functioning (Jacob, 2013), and may fail to appropriately assess psychosocial factors relevant to holistic treatment planning (Alonso, 2003; Carr, Higginson, & Robinson, 2003). The lack of inclusion or adequate representation of psycho constructs on common health measures of biopsychosocial wellbeing are considered to have limited utility for counselors and other mental health professions (Hattie, Myers, & Sweeney, 2004).

The development of robust, biopsychosocial assessment may provide strong utility for integrated collaboration in cancer care, and is a top research priority (Adler et al., 2008). Further exploration of biopsychosocial assessment models, particularly in

regards to psychosocial dimensions, may benefit from a multi-disciplinary approach. As previously stated, current biomedical efforts have fallen short in their attempts to close gaps in psychosocial care, and have notably lacked the expertise of psychosocial health professionals. Biomedical and psychosocial health professional's work in differing contexts, have different treatment priorities, and value differing research paradigms. However, as previously noted, holistic biopsychosocial models and biomedical models are not mutually exclusive; rather they may complement one another (Swarbrick, 2013).

It has also been suggested that the establishment of standard nomenclature could support improvements in multidisciplinary health research, as health fields drastically differ in terminology (Adler et al., 2008). In a recent article by Chambers et al. (2014), researchers noted the confusing amalgamation of research generation in cancer care, and highlighted a lack of common language and use of common models as a major barrier to research translation in clinical practice Chambers et al. also noted that empirical evidence grounded in theoretical models was "the expectation rather than the norm". To help fill gaps in research and oncological care, it may be critical for researchers to explore relationships between multi-disciplinary psychosocial models and constructs as a means of fostering the development of established multidisciplinary biopsychosocial paradigms and effective communication between professions.

This study aims to meet current recommendations that call for the development of appropriate screening tools for measuring a breadth of psychosocial factors. This study will also prioritize measuring psychosocial factors within a holistic biopsychosocial, which may be more appropriate in identifying the needs of cancer survivors. The

following section of this study reviews two biopsychosocial models intended to measure holistic wellbeing: Quality of Life (biomedical model) and Wellness (counseling model). Additionally, this study will prioritize a model of holistic wellbeing as the guiding framework for connecting these models, as it aligns with an empirically validated definition of health relevant to the psychosocial care of cancer survivors.

Assessment Models of Holistic Wellbeing

As previously stated, the WHO (1948) defines health in terms as "physical, mental, and social wellbeing, not merely the absence of disease." A definition of health not solely defined by the presence or absence of disease is particularly salient to those who live with chronic, and often life threatening diseases such as cancer. In the medical community, *quality of* life is the most common construct used to capture wellbeing. Conversely, *wellness* has been widely adopted as the primary framework for health among professional counselors.

Quality of Life

Quality of life (QoL) is defined by the World Health Organization (1993) as "as individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals expectations standards and concern." An alternate definition of defines QoL as "a patient's appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal" (Cella & Cherin, 1988, p. 70). Theoretically, quality of life includes a host of biopsychosocial constructs, most commonly physical, psychological, spiritual, and social wellbeing, that influence and comprise one's overall wellbeing –many of

which are subjective in nature and vary in importance from person to person (Lavdaniti & Tsitsis 2015; Sirgy, 2012). As discussed in chapter one, QoL has been linked to holism in that its parts (e.g., physical health and emotional wellbeing) also affect each other as well as the sum (Carr et al., 2003), and should be theoretically viewed at multiple contextual levels, including local and global contexts (Carr et al., 2003; Sirgy, 2012). The theoretical domain of quality of life, which includes multi-dimensional facets of human life including physical, emotional, mental, and social factors, seemingly justifies the use of QoL as an appropriate outcome variable for assessing the holistic wellbeing of a cancer patient.

It is commonly cited that there exists no universal accepted definition of QoL, despite the prolific abundance of "quality of life" research (Fayers & Machin, 2007; King & Hinds, 2012). The aim of including QoL in health outcomes measures is to be sensitive to patients' evaluation of their treatment and wellbeing (Carr et al., 2003). Foremost, QoL is subjective in nature, and varying definitions of QoL will be found from person to person (Fayers & Machin, 2007; Sirgy, 2012). Self-assessment or, in critical cases, assessment by caregivers is the benchmark standard for QoL assessment (Carr et al., 2003; Fayers & Machin, 2007). QoL assessments should be used to capture social and personal contexts of care, and may be particularly useful in prioritizing treatment options, monitoring patient satisfaction or response to treatment, and in screening for potential problems. It has been noted that non-biomedical items on QoL assessments may raise expectations for treatment outside of the scope of medical practice, as issues related to

emotional and social wellbeing are more appropriately treated by mental health providers (Carr et al., 2003).

Despite the fact that QoL has theoretical roots in the psychological tradition (Sirgy, 2012), current QoL research is often more closely tied to the medical model, which often focuses on the measurement of physical and mental decline and impaired role and social functioning (Carr et al., 2003). The appropriation of the term QoL is not unsurprising, as the medical model is the most widely used conceptualization in health research, despite evidence supporting a biopsychosocial or holistic health model. Connection to the medical model has caused significant gaps in measuring what should otherwise be a holistic well-being construct. Cella et al. (1993) noted that QoL is often measured in terms of functioning (1993), a finding which is consistent in many reviews of QoL (Carr et al., 2003; Lavdaniti & Tsitsis, 2015).

Current QoL research is further complicated by uneven use of the term *health related quality of life* (HQoL) in place of QoL. The term HQoL research was developed to differentiate HQoL from general QoL as an outcome variable limited to the subjective assessment of the *impact* of disease and its treatment across dimensions of social, physical, psychological, and somatic *functioning* (Revicki et al., 2000). While the recommended use of this term would in fact help differentiate the scope of QoL and HQoL measurement, HQoL and QoL are generally not discernable outcome variables in current QoL assessment and research, and the terms are often used interchangeably with very little explanation (Fayers & Machin, 2007). Furthermore, HQoL is an inappropriate construct for those interested in studying general wellbeing as the scope of HQoL only

includes physical, psychological, social, and somatic well-being variables in terms of how illness and treatment affect functioning in these areas. The model of HQoL prioritizes illness and impaired functioning in defining QoL, and does not consider the causal effects of psychological and social domains on physical wellbeing. The most widely uses assessment of QoL, the FACT-G (Cella et al., 1993), provides a useful framework for understanding QoL from a medical oncology perspective. The authors currently define the FACT-G as a measure of HQoL (Cella et al., 1993), however the assessment is often used to measure QoL, with little rationale or differentiation given.

Attention to gaps in assessment and treatment of the psychosocial needs of cancer patients is paramount. Several suggestions exist in the literature for meeting these needs. First, research of QoL would benefit from the perspective of disciplines operating outside of the medical model. The authors of the most widely used questionnaire, the FACT-G (Cella et al., 1993), have remarked that increased study of the multidimensional nature of QoL would greatly benefit QoL measurement, particularly in psychology related fields. A recent study by Connell, O'Cathain, and Brazier (2014) similarly supports the need for improved sensitivity of QoL assessment to mental health needs, and suggest the utility of qualitative research to identify domains of QoL that may be important to individuals with mental health problems. In general, QoL research and assessment would benefit from improved sensitivity to subjective dimensions of wellbeing (Moons, Budts, & De Geest, 2006), as well as positive/preventative factors (Carr et al., 2003). Study of QoL and similar constructs of wellbeing is still evolving, and may benefit from the inclusion of

perspectives from humanistic disciplines, such as counseling, which are known to value subjective determinants of wellbeing (Myers, 1992).

Wellness

Dunn (1961) was one of the first to define wellness in the health fields, describing wellness as "an integrated method of functioning which is orientated toward maximizing the potential of which the individual is capable, within the environment where he is functioning" (p. 9). While the term wellness has been widely used in several health communities to differing effect (Armentrout, 1993), the term has been effectively implemented and empirically studied in the field of professional counseling for several decades (Clark, Adams, Wilkerson, & Shaw, 2016; Hermon, 1995; Webster, 2004).

The counseling field has defined wellness as "the intentional seeking of mind, body, and spiritual health with the goal of fostering not only health, but wholeness" (Myers et al., 2000). Wellness has also been described as the foundation for the counseling profession (Myers, 1992). In wellness research, Hattie et al. (2004) noted the great need for development of counseling wellness models and assessments, as corresponding wellness models in other health fields overemphasized illness related variables, and deemphasized psychosocial variables.

The Wheel of Wellness was the first major conceptual model of wellness in the counseling field, and was created in as a conceptual model of wellness based on Alfred Adler's concept of holism, and the life tasks of work, friendship, and love (Sweeney & Witmer, 1991). Over time, the structure of the Wheel of Wellness was compared to interdisciplinary findings on the nature of wellness, and spirituality was placed at the

center of the wheel to represent the central point in which all other aspects of wellness emanate (Myers et al., 2000; Witmer & Sweeney, 1992). Spiritual wellness is probably one of the most developed and discussed topic in wellness literature across multiple fields, yet it is commonly not emphasized or included in psychosocial health research (Miller & Foster, 2010).

Through the development of the Wellness Evaluation Lifestyle (WEL), the Wheel of Wellness model was evidenced based on factor analysis of WEL items in comparison to the theoretical model (Hattie et al., 2004). This empirical data transformed the structure of the Wheel of Wellness into the Indivisible Self Model, which is also holistic in nature (Myers & Sweeney, 2004). In this model, a first order factor of wellness is followed by five-second order factors that include the creative self, the social self, the essential self, and the physical self. Each second-order factor has additional third-order factors. The authors of the model note the importance of systemic forces at local (family, community, neighborhood), institutional (education, government, etc), global (e.g., politics, culture), and chronometric (lifespan) variables.

Wellness theory has been historically more aligned with the psychological tradition, which operationalizes wellbeing in terms of one's subjective evaluation of life satisfaction (Hattie et al., 2004). Wellness-based assessment, which includes multiple input and output domains related to daily functioning (Myers et al., 2000), may provide more robust and nuanced assessment of psychosocial needs and general wellbeing of cancer patients than QoL. Whereas QoL assessment models utilized in health care have focused largely on physical and mental decline as a result of disease occurrence (Carr et

al., 2003), wellness-based assessment should include factors that impact holistic wellbeing, but are not solely the result of disease occurrence, such as stress management skills, cultural identity, and emotional awareness (Myers, 1992; Myers et al., 2000).

Similarly, the philosophy of counseling has been particularly influential in guiding current assessment models of wellbeing. The counseling profession has been extremely tentative to embrace areas of practice that over-rely upon a biomedical or disease model, in sharp contrast to the development of QoL models utilized by medical professionals, and have preferred to base our practice in wellness and humanistic-centered practices (Myers, 1992). In fact, hesitancy of counseling professionals to rely upon the medical model has likely pushed our field to value other aspects of health –such as personal strengths, multicultural contexts, social justice, spirituality –which are often ignored in the greater health care community as core ethical competencies of our practice (American Counseling Association, 2014).

Connections Between Models

In looking explicitly at the FACT-G as a model for QoL, and the Indivisible Self Model of wellness, there are several apparent similarities. Both perspectives of wellbeing are measured in a variety of contexts which both include factors related to emotional, social, and physical wellbeing (Cella et al., 1993; Myers & Sweeney 2005a; Myers & Sweeney 2005b). However, emphasis of factor categories varies between models. The FACT-G model of QoL, which is derived within the medical model, provides greater emphasis on functioning, and assesses factors of physical wellbeing that are commonly impacted by cancer (e.g., severity of fatigue) (Cella et al., 19993). Conversely, wellness

models may provide more nuance for psychosocial factors, but may include definitions of physical wellbeing that presume idealistic physical functioning (Roscoe, 2009). Notably, the Indivisible Self model defines the second order factor of physical wellness through third order factors: nutrition and exercise (Myers & Sweeney, 2004). These different perspectives on physical wellness may be more salient with certain populations than others (e.g., physical wellness in medical populations is likely best assessed through Cella's factors). The Indivisible Self Model, in contrast to the simplicity of the FACT-G measurement model of QoL, assesses creative wellbeing (thinking, emotions, control, work, positive humor as third level items on this factor), coping (leisure, stress management, self-worth, and realist beliefs as third level items on this factor), social wellbeing (friendship and love), and the essential self (spirituality, gender identity, cultural identity, and self-care as third order factors) (Myers & Sweeney, 2004). Similarly, the complexity of the Invisible Self Model is indicative of the philosophical lens of the counseling profession: mental health practitioners are accustomed to assessing mental health and wellbeing through a complex system of factors, rather than limited concrete variables. Mental health models of wellbeing may be more appropriate in assessing complex psychosocial variables, but may be less appropriate for capturing biomedical variables salient for assessing physical wellbeing.

Quality of life and wellness as outcome variables (keeping current limitations of QoL assessment in mind) are intended to be holistic in scope. This holistic perspective allows for the incorporation of many unaddressed or understudied determinants of wellbeing in multiple contexts. Used in tandem, these models may provide particularly

useful information in research domains which would benefit from the strengths of both; namely research which combines elements of social, emotional, and psychological wellbeing (Wellness perspective strengths) and physical and mental function as altered by physical illness (QoL assessment strengths).

At their core, concepts such as wellbeing, wellness, and QoL are only measurable from the subjective viewpoint of each individual; these definitions of health must include personal meaning making and values that are specific to individual culture and context (Sirgy, 2012; Hattie et al, 2004). Current recommendations for wellbeing assessment and research in multiple fields affirm the need for prioritizing patient perspectives while maintaining rigorous research standards (Fayers & Machin, 2007). Both the study of and interventions to increase wellbeing in healthcare should include perspectives of professionals with the appropriate expertise (biomedical or mental health) while maintaining priority of patient perspectives. Notably, patient self-assessment of wellbeing may often differ substantially from the judgment of medical care providers, as well as other patients (Fayers & Machin, 2007; Adler et al., 2008). Similarly, the importance of wellbeing factors, and how incorporate them into individualized treatment plans will also vary between patients are care providers (Fayers & Machin, 2007). Appropriate measure of wellbeing should also include patient strengths and resources. Research and medical treatments that rely on solely on a "pathology" model of health, focused on the measurement of physical and mental decline, are thought to inevitably underestimate individual's wellbeing (Carr et al., 2003).

Summary

Despite empirical evidence supporting the need for evidence-based psychosocial cancer care, the receipt of quality psychosocial care among cancer survivors is considered the exception rather than the norm (Adler et al., 2008; Chambers, et al. 2014). Particular gaps have been noted in the identification and treatment of mental health needs among cancer survivors (Forsythe et al., 2013; Holland et al., 2011).

While the need for psychosocial care within oncology is clear, evidence-based practices for psychosocial needs in medical settings such as oncology are still in their infancy. The use of integrated, holistic biopsychosocial models have been recommended as critical frameworks in approaching complex health needs such as cancer (Hatala, 2012; McGrady & Moss, 2013). As such, this study will utilize models of holistic wellbeing to conceptualize the psychosocial needs of cancer survivors, and will emphasize the identification of mental health symptomology as a critical facet of holistic biopsychosocial assessment among cancer survivors.

Additionally, the need for increasingly holistic models of health care and evidence-based treatments will require shifts in previously established boundaries between health professions and their theoretical perspectives, creating both new challenges and new opportunities within the new landscape of oncology and healthcare (Chambers et al., 2014; McGrady & Moss, 2013). Assessment models and evidenced based treatments that attend to holistic wellbeing—biomedical and psychosocial facets of health—will require increased collaboration between medical and mental health professionals, as well as patient perspectives. Specifically, the philosophical perspectives,

evidence based assessment, and treatment modalities of mental health professionals in particular must be increasingly utilized, as the assessment and treatment of psychosocial factors of health lie more firmly within their expertise. Furthermore, as holistic wellbeing can only be understood through incorporation of subjective personal experiences, the inclusion of cancer survivor perspectives of psychosocial needs will be included. This process will involve multiple steps. This study will explore the utility of multidisciplinary models of holistic wellbeing in the identification of significant psychosocial needs of cancer survivors, operationalized in this study as depressive symptomology. Subsequently, significant psychosocial factors related to the cancer experience as identified by cancer survivors will be explored. Additionally, exploration of biomedical and counseling models of holistic wellbeing compared to the self-identified psychosocial needs of cancer survivors will be presented. In this way, the perspectives of medical care providers, mental health providers, and cancer survivors will assist in the exploration of more holistic biopsychosocial models for utilization within cancer care.

CHAPTER III

METHODOLOGY

Introduction

In Chapters I and II, the rationale and literature basis for the study of quality of life and wellness within cancer care were presented. The review of the literature demonstrated a lack of clinical response to strong research recommendations to better attend to non-bio-medical facets of holistic wellbeing in cancer care, as well as the strong need for improved assessment and treatment of mental health symptomology among cancer patients and survivors. Currently, the assessment of quality of life (QoL) or health related QoL, is often utilized as the de facto screening for holistic wellbeing within cancer care. Problematically, QoL and health related QoL often are more sensitive to medical functioning, and do not always provide adequate assessment of factors which may better capture and predict mental and emotional wellbeing as key facets of holistic wellbeing. This study, in line with recent researcher recommendations, seeks to explore the utility of multidisciplinary assessment models of holistic wellbeing in their ability to account for significant mental health symptoms that may exist in conjunction with the experience of living with a cancer diagnosis. In particular, this study focused on symptoms of depression, as depressive symptomology are considered pervasive and significant during every stage of the cancer journey, and susceptible to the influence of a variety of psychosocial factors relevant to holistic wellbeing (Block, 2010; Burton,

Galatzer-Levy, & Bonnano, 2014; Chapman, Perry, & Strine, 2015). This study assessed holistic wellbeing through two disciplinary/theoretical perspectives, the prevailing medically-based health related QoL perspective (as measured by the commonly used FACT-G; Cella, et al.,1993), and a counseling based model of holistic wellness (as measured by the FFWEL-A; Myers & Sweeney, 2005a), and their ability to account for depressive symptomology among cancer survivors. Similarly, as theoretical models are only as useful to the degree they correspond with the realities they seek to describe, a mixed method approach was used to include cancer survivor perspectives on the relationship between holistic wellbeing, mental health, and the experience of a cancer diagnosis.

In this chapter, the researcher provides a detailed description of the research questions, hypotheses, participants, instrumentation, procedures, and data analysis for this study. The researcher also has included an overview of the study design.

Sequential Explanatory Mixed Method Design

The researcher employed a sequential explanatory mixed methods design. The sequential explanatory mixed method design entails the collection of quantitative data followed with a collection of qualitative data in relation to a related set of research questions, and a final analysis of total findings that integrates quantitative and qualitative conclusions. The design utilizes the strengths of quantitative and qualitative methods to capture more intricate trends and details in research problems (Ivankova, Creswell, & Stick, 2006). Study of holistic wellbeing has been previously described as particularly complex (Carr, Higginson, & Robinson 2003; Larson, 1999); thus, a research design that

is intended to increase complexity in findings is appropriate. The collection of qualitative data, which prioritizes individual participant experiences and perspectives, is particularly appropriate in the study of wellness and QoL, as these constructs are extremely subjective (Sirgy, 2012). This study was conducted in two phases, with the quantitative occurring first (Phase 1) and the qualitative occurring second (Phase 2). An integrated analysis of results from both phases was completed after Phase 2. The use of a subset of the quantitative participant sample to explore the qualitative research questions of this study provided a richer analysis of connections between these findings related to the psychosocial needs for holistic wellbeing among cancer survivors (see Figure 1).

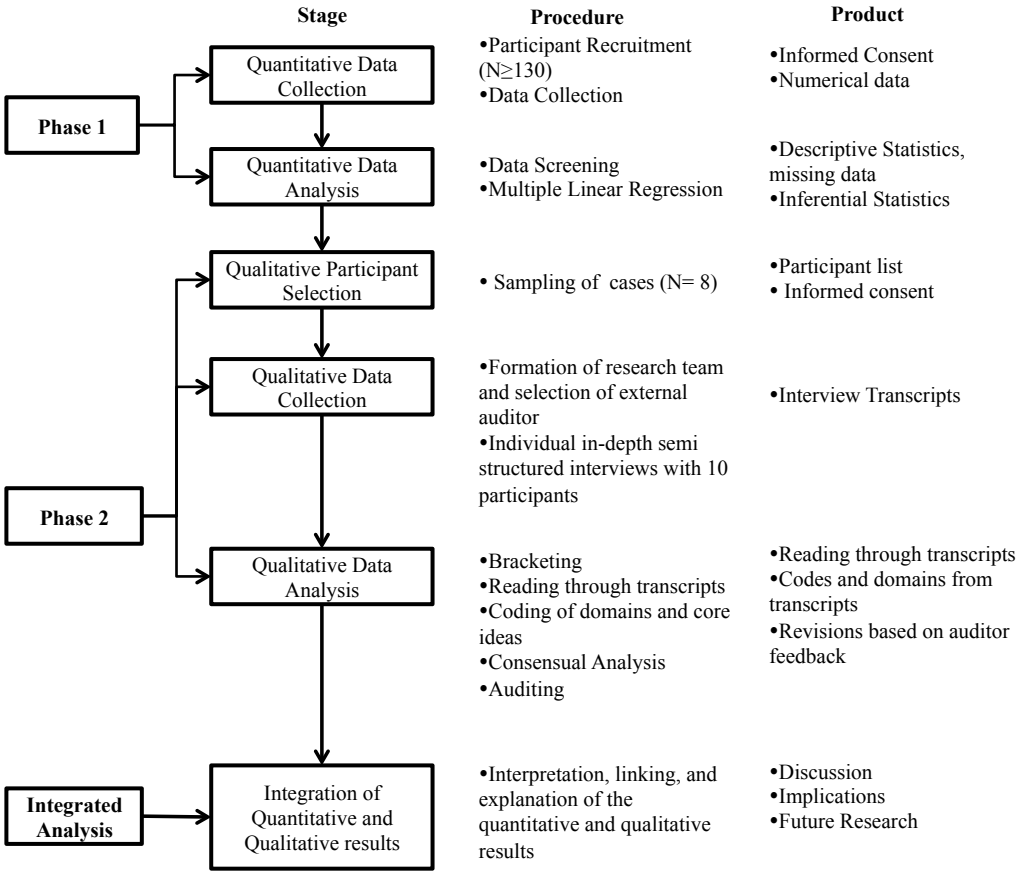
Phase 1 explored the extent to which two models of wellbeing, which were created through discipline-specific theoretical orientations, assess for relevant psychosocial factors that are known to predict depressive symptoms. Depressive symptoms are common among cancer survivors (Honda & Goodwin, 2004; Irwin Henderson, Knight, & Pirl, 2014), and are thought to impact holistic wellbeing during the cancer experience (e.g., Breitbart, Rosenfeld, Pessin, & Kaim, 2000; Fresche de Souza et al., 2014; Nakash et al., 2014). The researcher also explored which model (wellness, QoL) was a stronger individual predictor of depression among cancer survivors. The researcher additionally explored shared and unique variance between the models.

Phase 2 explored relevant psychosocial factors to holistic wellbeing during the cancer experience as reported by cancer survivors using consensual qualitative research (CQR) methodology. The researcher utilized a semi-structured interview format to explore both negative and positive psychosocial factors. The primary researcher, along

with a research team, explored themes and prevalence of survivor-identified psychosocial factors.

The final integrated analysis compares quantitative findings to the experiences of cancer survivors. This approach allows the researcher to compare a theoretically consistent concept of wellbeing, one that is subjectively defined (Miller & Foster, 2010; Sirgy, 2012), to multidisciplinary conceptual models of wellbeing. The researcher has highlighted significant psychosocial constructs from each phase, and has note shared and unique findings between phases.

Figure 1. Visual Model for the Sequential Explanatory Methods Design



Research Questions and Hypotheses for Phase 1: Quantitative

The following research questions and respective hypotheses were examined in the quantitative portion of the study in Phase 1.

Research Question 1: Does QoL (operationalized by FACT-G second-order subscales: physical wellbeing, functional wellbeing, social wellbeing, and emotional wellbeing) or wellness (operationalized by the FFWEL-A second-order subscales: physical self, social self, coping self, essential self, and the creative self) explain more variance in depression scores among cancer survivors?

Hypothesis 1: Wellness will provide a broader assessment of factors that are associated with mental health outcomes and symptomology, and will explain more variance in depression scores among cancer survivors.

Research Question 2: What shared and unique variance do QoL and wellness have when explaining depression scores?

Hypothesis 2: The variance in depression scores accounted for by QoL and wellness will have more shared variance than unique variance.

Research Questions for Phase 2: Qualitative

The following questions are qualitative; therefore no hypotheses were made.

Research Question 3: What do cancer survivors perceive as salient psychosocial needs or factors currently and previously in treatment?

Research Question: Integrated Analysis

Research Question 4: Are current models consistent with the identified salient psychosocial factors in the lived experiences of cancer survivors?

Phase 1: Quantitative Portion

Phase 1 entails a quantitative, cross sectional correlation design.

Sample and Participant Selection

The researcher obtained permission from the Institutional Review Board at The University of North Carolina at Greensboro prior to conducting the survey. The populations under study were adults (age 18 and up) who met the following criteria: (1) had recently entered into (full or partial) remission of cancer, (2) were within five years of their cancer diagnosis, and (3) underwent surgery, radiation and/or chemotherapy treatment. Cancer survivors who are within three years of their diagnosis, considered to be in the *extended survival* category of cancer survivorship, have generally finished treatment but remain at an elevated risk of re-occurrence (Faguy, 2013), although cancer survivors are not considered to be in long-term survival until after five years (Faguy, 2013; National Cancer Institute, 2016b). In addition to having experience with cancer-related stressors, individuals in the extended survival stage of cancer survivorship must also cope with stressors often associated with the possibility of recurrence (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006). It is critical that participants be within a few years of their diagnosis, as they will be asked to reflect upon past and current psychosocial needs as they relate to holistic wellbeing during the cancer experience during and after treatment. Researchers have highlighted the role of time and adjustment in making sense of psychosocial aspects of wellbeing during and after cancer treatment (Boerger-Knowles & Ridley, 2014); participants within a few year of their diagnosis and conclusion of their treatment will have had time to process the effects of cancer and its

resultant treatment and may be more likely to accurately assess their own psychosocial needs. Similarly, as cancer types and treatments vary widely, it is critical to assess individuals who have experienced a diagnosis severe enough to require surgery, chemotherapy and/or radiation, as these individuals are considered to experience more negative effects on general wellbeing due to the severe side-effects often associated with these treatments (Browal et al., 2008; Choi et al., 2014; Faguy, 2013; Houldin, 2000).

According to G*Power (Version 3.1.9.2; Faul, Erdfelder, Buchner, & Lang; 2009), to obtain a moderate effect size and power of .80 to compute the data analysis in Phase 1 of the study an estimated sample size of at least 114 was needed. In order to provide a buffer for missing data, the researcher obtained 147 participants for Phase 1. Participants were recruited online (nationally) using convenience sampling methods.

Instrumentation

Consenting participants completed three standardized instruments and a demographic questionnaire. What follows is a description of the development and psychometric properties of the respective instruments.

Demographic questionnaire. Participants completed a demographic questionnaire containing questions about the following information: gender, age, date of diagnosis, diagnosis type and stage, treatment category, remission status, length of time in remission, race, relationship status, housemates, and current employment status (Appendix B).

Quality of life. The Functional Assessment of Cancer Therapy Scale, version 4 (FACT-G; Cella et al., 1993) is a 27-item assessment measuring QoL among cancer

patients (all cancer types) (see Appendix B). The authors of the FACT-G describe QoL as a "subjective, multidimensional construct" which is intended to "summarize the combined impact of disease and treatment and the trade-off between the two"(Cella et al., 1993 p.571, p.570). The FACT-G is the primary assessment in the FACIT (Functional Assessment of Chronic Illness Therapy; Webster, Cella, & Yost, 2003) Measurement System, which includes over 40 different FACIT scales available in more than 45 different languages. The current version contains four subscales and a total QoL score. The four subscales of physical wellbeing (PWB, 7 items), emotional wellbeing (EWB, 6 items), social wellbeing (SWB, 7-items), and functional wellbeing (FWB, 7 items) were developed to allow for a more detailed summary of specific aspects of QoL (Cella et al., 1993). Participants respond to items using a five-point Likert scale (with 0 = *Not at all*, and 4 = *Very much*). The FACT-G has a total score range of 0 to 108, with a lower score indicating lower QoL. The highest possible score is 28 for the PWB, SWB, and FWB subscales individually, and 24 for the EWB subscale. The self-administered assessment takes 5 to10 minutes to complete.

The PWB scale is intended to measure physical aspects of QoL, and includes items such as "I have a lack of energy" and "I have pain." The EWB scale is intended to measure emotional aspects of QoL, and includes items such as "I feel sad" and "I worry about dying." The SWB scale is intended to measure social wellbeing aspects of QoL, and includes items such as "I feel close to my friends" and "I get emotional support from my family." The FWB scale is intended to measure functional wellbeing aspects of QoL, and includes items such as "I am able to enjoy life" and "I am content with the quality of

my life right now." The subscales have been found to have adequate reliability with Cronbach alpha coefficients for each subscale as follows: PWB = 0.82, EWB = 0.74, SWB = 0.69, and FWB = 0.80, with an overall alpha of .89 (Cella et al., 1993). Cella, Hahn, and Dineen (2002) reported that the PWB, EWB, FWB, and overall QoL score are responsive to patient rated meaningful changes over time, but noted a lack of responsiveness in the SWB scale. Despite lower reliability in the SWB, which will be a limitation in this study, the FACT-G is prevalent in its use in cancer care.

The FACT-G (Cella et al., 1993; Cella, Hahn, & Dineen, 2002) was chosen for this study as it is a highly utilized assessment of QoL in cancer care across the globe. The FACT-G was created in five phases that included item generation from 45 cancer patients and 15 oncology specialists (Cella et al., 1993). After revisions, 38 items were generated and sent for review to 135 cancer patients and the original 15-oncology specialists. This method of item generation is significant as it aligns with QoL theoretical boundaries of attempting to define wellness from the subject's point of view (Fayers & Machin, 2007; Sirgy, 2012); however, the inclusion of oncologists in item generation and review necessarily influences the construct of assessed QoL to be more medically-oriented than a purely patient-generated construct of QoL. Although this scale is still heavily geared towards measuring the effects of illness on functioning in these areas, the authors were intentional in their attempts to improve sensitivity to non-physical factors of QoL (Cella et al., 1993). Sample data collected from 545 cancer patients who completed the initial FACT-G demonstrated content, construct, and face validity (Cella et al., 1993). The FACT-G has been shown to have strong Pearson product-moment correlation

coefficient with the Functional Living Index-Cancer (.79) and the BriefPOMS (-.65)(Cella et al., 1993). The current 27-item version was reduced for the purpose of simplification and clarity, and to decrease patient burden in completing the assessment; it no longer includes items related to patient doctor relationship (Webster, Cella, & Yost, 2003). The FACT-G has been shown to be sufficiently valid and reliable in measuring QoL in various populations that include rural communities, the elderly, and cancer patients across the globe (Costet, Lapierre, Benhamou, & Le Galès, 2005; Overcash, Extermann, Parr, Perry, & Balducci, 2001; Thomas, Pandey, Ramdas, Sebastian, & Nair, 2004; Winstead-Fry & Schultz, 1997). Within the current sample for this study, the internal consistency of items on the FACT-G subscales ranged from .86 (Functional Wellbeing, 7 items) to .91 (Physical Wellbeing, 7 items). These estimates of internal consistency support the reliability of the items on this measure for use within this sample (see Table 1).

Wellness. The Five-Factor Wellness Inventory, Adult (FFWEL-A), previously the 5F-WEL, is a 91-item questionnaire designed to assess holistic and component-specific wellness, and comes from a counseling perspective (Myers & Sweeney, 2005b)(Appendix B). The FFWEL-A was developed through structural equation modeling of a large database (n = 3,043) using the Wellness Evaluation of Lifestyle (Hattie, Myers, & Sweeney, 2004). The self-administered questionnaire takes 10 to 20 minutes to complete (Myers & Sweeney, 2005b).

The statistical model for the FFWEL-A has a single higher order factor of wellness that describes one's general wellbeing or holistic wellness. There are five

second-order factors, or subscales of the FFWEL-A, the Physical Self (10 items), Social Self (8 items), Coping Self (19 items), Essential Self (16 items), and Creative Self (21 items), within which are 17 third-order factors. For the purpose of this study the first and second order factors will primarily be used. The Physical Self is the "the biological and physiological processes that comprise the physical aspects of our development and functioning" (Myers & Sweeney, 2005a, p. 33). This subscale is comprised of two third-order factors: Nutrition and Exercise. The Social Self refers to "social support from connection with others"(Myers & Sweeney, 2005a, p.33), and includes two third-order factors of Friendship and Love. The Coping Self is conceptually comprised of the different factors that "regulate our responses to life events and provides a means for transcending their negative effects" (Myers & Sweeney, 2005a, p. 33). This second-order factor includes four third-order factors: Leisure, Stress Management, Self-Worth, and Realistic Beliefs. The Essential Self refers to the "meaning-making process in relation to life, self, and others" (Myers & Sweeney, 2005a, p. 33). Third-order factors for the Essential Self include Spirituality, Gender Identity, Cultural Identity, and Self-Care. The Creative Self is "the combination of attributes that each of us forms to make a unique place among others in our social interactions and to interpret our world" (Myers & Sweeney, 2005a, p. 33). This second-order factor includes five third-order factors: Thinking, Emotions, Control, Work, and Positive Humor. In addition to the 74 items on these scales, another 17 items comprise the measure. Additional items include questions related to context (local, global, institutional, and chronometrical) as well as one validity index (VI) item (Myers & Sweeney, 2005b).

The 91 items on the FFWEL-A are rated using a four-point Likert-type scale: *strongly agree, agree, disagree, strongly disagree* (Myers & Sweeney, 2005b). Scores range from 25 to 100, with higher scores indicating higher wellness. The FFWEL-A evidenced reliability for total wellness (.94) and internal consistency for the five second-order factors averages to .92. Additionally, the third order factors also have evidence of internal consistency of items (with Cronbach's alpha ranging between .79 to .88)(Myers & Sweeney, 2005b). Cronbach's alpha coefficients for each subscale are as follows: Physical Self = 0.90, Social Self = 0.94, Coping Self = 0.92, Essential Self = 0.91, and Creative Self = 0.93 (Hattie et al., 2004). Although they can be used as stand-alone subscale, the second-order factors also load onto the single wellness factor (Myers & Sweeney, 2004). Validity tests for the FFWEL-A have demonstrated concurrent validity with similar constructs, such as the Testwell, the Coping Response Inventory (CRI), Measures of Psychosocial Development (MPD), and the Inventory of Self Actualizing Characteristics (ISAC) (Hattie et al., 2004). The authors of the instrument report evidence of convergent and divergent validity of the scales relative to mattering, gender role conflict, social interest, spirituality, moral identity, ethnic identity, body image, and life satisfaction from the use of the FFWEL-A in numerous studies (Myers & Sweeney, 2004). In the current study, the FFWEL-A internal consistency of items ranged from .83 (Essential Self, 16 items) to .91(Creative Self, 21 items), supporting the reliability of this measure for use within this sample (see Table 1).

Depression. The Center for Epidemiologic Studies Short Depression Scale (CES-D-10) is a ten-item self-report questionnaire designed to assess depression in the general

adult population (Andersen, Malmgren, Carter, & Patrick, 1994)(Appendix B). Responses are rated on a 4-point likert scale from 0 (*less than one day*) to 4 (*5-7 days*), and the self-administered assessment takes about 5 minutes to complete. The assessment is a condensed version of the Center for Epidemiological Studies Depression Scale (CES-D), which was originally developed as a 20-item self report measure of depressive symptomology among clinical and general adult populations (Radloff, 1977). The CES-D-10 has a score range of 0 to 30, with scores of 10 or higher indicating the presence of significant depressive symptomology (Andersen et al., 1994). The CES-D-10 is not designed as tool for clinical diagnosis of depression, as the CES-D and the CES-D-10 scales are based upon general symptoms of depression and are not sensitive to levels of severity of depressive symptomology (Andresen et al., 1994; Radloff 1977). The CES-D-10 has good internal reliability (Cronbach's α=0.89), test re-test stability, and construct validity (Andersen et al., 1994; Radloff 1977). The assessment has been shown to have discriminant validity, having low correlations with dissimilar scales (e.g., correlation with Bradburn Positive Affect scale =-0.55) and high correlations with other depression scales (e.g., correlation with SLC-90 depression scale = 0.83). The CES-D has been shown to have good internal consistency in clinical and general populations (Björgvinsson et al., 2013). In the current study, the CES-D-10, a single scale measure of depression, was found to be highly reliable ($\alpha = .86$; see Table 1).

Table 1

Internal Consistency of Measures

	Cronbach's Alpha	# of items
FACT-G PWB	0.909	7
FACT-G SWB	0.885	7
FACT-G EWB	0.888	6
FACT-G FWB	0.863	7
FFWEL-A COP	0.870	19
FFWEL-A CRTV	0.909	21
FFWEL-A ESS	0.831	16
FFWEL-A PHY	0.898	10
FFWEL-A SOC	0.903	8
CES-D-10	0.863	10

Note: PWB = Physical Wellbeing; SWB = Social Wellbeing; EWB = Emotional Wellbeing; FWB = Functional Wellbeing; COP = Coping Self; CRTV = Creative Self; ESS = Essential Self; PHY = Physical Self

Procedures

To obtain a broad sample of participants, convenience sampling procedures were used. The researcher collected data through an electronic survey program called Qualtrics. The first recruitment strategy used was the recruitment of participants through social media resources via convenience sampling. The researcher targeted public and closed Facebook cancer survivor support groups, which included those geared towards general and specific cancer type populations. In closed groups, the researcher contacted the group administrator of a specific group and briefly explained the purpose of the study

through a standardized message. Upon obtaining permission in closed groups, the primary researcher posted a short recruitment statement and the link to the external web page. The researcher posted the same message in open groups. As incentive for participation among individuals recruited through social media, the primary researcher agreed to donate up to $2 to a charitable foundation of the participant's choice. Seventeen participants were obtained through the initial recruitment strategy.

A secondary recruitment strategy included paid sampling through a secondary source, Qualtrics. The researcher paid a specified fee to Qualtrics in exchange for 130 completed survey packets. Qualtrics agreed to replace any surveys with missing or suspicious data until 130 surveys had been completed. Qualtrics accessed participants found within various participant panels within their network to and shared the survey link with possible participants. Individuals recruited through Qualtrics were incentivized by Qualtrics. Once the initial target number for the sample was reached, the primary researcher reviewed the data for any missing or suspicious responses. The primary researcher identified five sample participants that appeared to provide questionable responses, at which point Qualtrics removed the identified responses and found additional participant responses to replace the data until a satisfactory data set was obtained.

The Qualtrics survey link included (a) a description of study criteria, (b) an electronic consent form (Appendix A), (c) instructions for completing the assessment, (d) a demographic questionnaire (Appendix B), and (e) three questionnaires (Appendix B). Upon completion of the study, participants were asked to indicate (via "yes" or "no" checkbox) if they were interested in participating in a subsequent interview discussing

their perspective on their holistic wellbeing throughout their experience with cancer. Participants who checked "yes" were asked to provide an email address for further contact. Email addresses provided were transferred into an Excel document, which was kept on a password-protected computer.

Individuals who elected to participate in the study were encouraged to print a copy of the informed consent for their records, as it outlined the purpose of the study, efforts made by the researcher to ensure confidentiality, potential risks of participation, and the voluntary nature of the study. Individuals who elected to be considered for, and who were eventually contacted for the semi-structured interviews required additional consent in Phase 2 of the study. After analyzing Phase 1 results from Phase 2, and collecting necessary demographic information, all email addresses were deleted to maintain the confidentiality of Phase 2 participants.

Data Analysis

Upon completing data collection from Phase 1 of the study, the data stored in Qualtrics was imported into the Statistical Package for the Social Sciences 20 (SPSS) for data analysis. Prior to completing data analysis for the specified research questions, the data was reviewed for any missing data. Demographic data was summarized by SPSS using the descriptive statistics function.

In order to determine the amount of variance in depression scores with the second-order subscales of the FACT-G and FFWEL-A as predictors, multiple linear regression analysis was used to answer research question 1: Does QoL (as measured by the FACT-G and its subscales) or wellness (as measured by the FFWEL-A and its

subscales) explain more variance in depression scores among cancer survivors? Predictors were entered using the forced entry hierarchical regression method. According to Field (2014, p. 322), the method is similar to hierarchical regression in its reliance of a theoretical foundation in choosing predictors, but unlike simple hierarchical regression, the researcher makes no decision as to the order predictors are entered. Many researchers consider this method the most appropriate for theory testing (Field, 2014; Studenmund & Cassidy, 1997). A commonality analysis (Nimon, 2010) was conducted to explore the unique and shared variance of QoL and FFWEL-A in order to answer the second research question.

Phase 2: Qualitative Portion

Consensual Qualitative Research

As previously discussed, there exists a great deal of research literature on topics of psychosocial factors in cancer care, but there have been a noteworthy lack of qualitative studies to ground and refine current understandings of holistic wellbeing during the cancer experience. Furthermore, QoL and holistic wellbeing are subjective in nature, and study of these constructs should optimize methods that provide rich and descriptive data (Sirgy, 2012). A mixed-methods study is useful in exploring connections between current methods of assessment of wellbeing in cancer care and the experiences of wellbeing among cancer survivors. To optimize exploration of subjective perspectives of wellbeing among cancer survivors, a Consensual Qualitative Research (CQR) study was employed. As the primary topic of this study involves the exploration of non-bio-medical aspects of wellbeing, or psychosocial wellbeing, among individuals who

experience a diagnosis of cancer, the interview questions were created to answer research question 3: What do cancer survivors perceive as salient psychosocial needs or factors currently and previously in treatment?

CQR was first developed in the 1990s by Hill, Thompson, and Williams (1997) as a scientifically rigorous yet phenomenologically sensitive qualitative study design. Similar to many qualitative research methods, CQR promotes the use of multiple researchers drawing individual conclusions with qualitative data, open dialogue to discuss identified domains (themes) and core ideas, reaching consensus of domains and core ideas as a team, use of an external auditor to reduce bias or faulty assumptions, and a systematic review of principal conclusions as to their representativeness of participant cases (Hill, 2012; Hill et al., 1997). CQR also places great emphasis on respecting the participants, as participants are considered to be experts of their inner experiences (Hill, 2012; Hill et al., 1997). The four identified steps in the CQR process include: (a) the use of semi-structured interviews with open-ended questions, (b) the use of domains to sort data into broad themes, (c) summarizing core ideas from each domain, (d) the use of cross-analysis to determine and confirm patterns across cases in the data (Stahl, Taylor, & Hill, 2012)**.**

Sample and Participant Selection

Participants for Phase 2 included individuals from Phase 1 of the study, and therefore met all participant requirements previously mentioned. Participants who consented to and completed the quantitative portion of the study were given the option of electing to be considered for a follow up interview by the primary researcher, as

previously mentioned. Guidelines CQR generally require 8 to 15 participants to meet saturation, which is the point in data collection at which new cases do not change the data analysis results (Hill et al., 1997). For the purposes of this study, 8 participants were sampled from the pool of Phase 1 participants who elected to be considered for a follow-up interview. Participants were contacted via the email they provided in Phase 1. Consent forms were provided and returned via email, or completed online via a checkbox in Qualtrix.

As incentive for participation, participants who were selected and completed the semi-structured interview received a $10 e-gift card to their choice to Target, Panera, or Starbucks. Participants who completed the semi-structured interview received their incentive within a week of the scheduled interview time.

The Research Team

A research team was chosen prior to the pilot study. CQR research teams are recommended to include 3-5 team members to conduct analysis, and one to two auditors to review the analyses (Hill et al., 1997). This study included the primary researcher, two additional research team members, and an external auditor. Research teams are often chosen by convenience according to those who are willing to offer their time and support, although it is also recommended that team members have some interest or experience with the topic of study (Hill, 2012). As the current study was a part of a doctoral dissertation, participants on the team included a dissertation committee member and fellow doctoral students. Research team members were asked to participate in the study via email or during face-to-face meetings.

Student researcher. The student researcher was a 28-year-old Caucasian female who enrolled in a counseling and counselor education doctoral program. During the time of the study, she held a master's degree in counseling, and was licensed professional counseling associate (LPCA) with five years of counseling experience. The primary researcher has previous experience providing counseling services at a local outpatient cancer facility, which deeply informed her current research interests. As the researcher may have had bias related to the wellness needs of cancer survivors based on her previous experience providing mental health services to the population of study, it was critical to include researcher team members with less familiarity with the population. The student researcher, prior to conducting the pilot study, read extensively on the topic of CQR, and received guidance and direction in the process of designing and implementing the study from dissertation committee members and members of the research team who have more extensive experience.

Team member 2. The second member of the research team was a Caucasian female who, at the time of the study, was pursuing her PhD in Counseling and Counselor Education. The second research member had experience with two previous CQR studies, as well as other research methods. She had no previous experience researching chronically ill populations such as cancer survivors.

Team member 3. The third team member is a Caucasian female who, at the time of the study, was pursuing her PhD in Counseling and Counselor Education. Prior to the current study, the third team member had no formal experience with CQR. Additionally,

the third team had worked in several grief related clinical populations, which overlapped with some of the content of the current study.

Auditor. The research team auditor was a Caucasian male with a PhD in Counseling and Counselor Education. He had experience with CQR and other research methods prior to the current study, and has co-authored multiple publications on wellness. At the time of the study, the auditor served as the director of a graduate program-counseling clinic, and was a dissertation committee member for the student researcher.

Research team preparation and expectations. In preparation of Phase 2 of the research study, the research team met to establish common goals of the study. As this is a mixed methods study, the primary researcher discussed the purpose of the CQR as an integral part of the larger sequential explanatory design, as well as the pre-selected research questions. Hill (2012) outlines the necessity of discussing roles on the team, as well as dynamics of power differentials and trust in this team. Hill (2012) recommends that researcher participants have some training or experience in CQR before the study begins, and optimally recommends that at least two team members have CQR experience to allow for more informal training in the beginning of the process.

The research team completed a bracketing exercise prior to data analysis. Bracketing, a concept taken from phenomenological research, involves the researchers suspending their own interpretations (e.g., not looking to fit responses to particular theories) in order to enter into the unique world of participants (Hycner, 1985). It is also critical that biases discussed during the initial bracketing exercise are continually

examined throughout the CQR process in order to improve validity of results (Hill, 2012).

Bracketing process. During the initial research team meeting, members discussed the concept of bracketing and acknowledged their own experiences or expectations of the topic that might bias their ability to enter into the unique world of the participant. An environment of safety and trust was emphasized in this meeting, and will be in subsequent meetings, in order to maintain the collaborative atmosphere that CQR requires (Hill et al., 1997).

All of the research team participated in the bracketing exercise held during the first research team meeting prior to completion of the pilot study. Prior to the meeting, all team members were sent a brief outline of the full study, as well as the semi-structured interview questions specific to Phase 2. The research team identified their personal experiences with the population of the study. All research team members acknowledged some personal familiarity with cancer survivors, which included family members and friends who have experienced cancer. One research team member acknowledged being closely tied to the cancer experience of a family member who fought through breast cancer, and acknowledged that she may have some emotional responses to the participant transcripts. All of the research team members acknowledged the emotional impact of cancer, as well as the need for openness in discussing the impact of the interview transcripts during the CQR process.

There were several implications drawn from the bracketing exercise. First, it was determined that some potential bias in the study will include high expectations that

psychosocial factors such as spirituality, social wellbeing (relationships), and personal coping strategies will be significant factors that emerge form the CQR process. All of the research team members are counselors and are trained to value psychosocial wellbeing. The bracketing responses included biases towards both positive and negative states of psychosocial wellbeing (e.g., "cancer survivors won't be as well emotionally," "survivors will have a renewed outlook on life"). The bracketing data suggested the possibility for multiple assumptions among the research team, including assumptions that cancer survivors have mainly negative experiences or that cancer survivors display increased resiliency than the general population. It was agreed upon during the review of the data that biases and expectations should be continually brought up throughout the CQR process to limit personal assumptions.

Procedures

Semi-structured interviews. Once the researcher received the consent form, participants were sent a list of interview questions. As participants were asked to reflect upon their experiences over a time span of up to three years, providing the questions in advance is appropriate, as it will allow time to reflect upon their experiences (Hill, 2012). Additionally, as participants were geographically dispersed, interviews were held over the telephone. It has been suggested that telephone interviews may also limit fewer socially desirable responses (Hill et al., 1997). During scheduled interview times, the primary researcher called participants over the phone and recorded the conversations using a recording device, which was kept in a locked drawer in a locked building when not in use. As QoL and wellness are discipline-specific concepts, the primary researcher

also gave a brief description of "general wellbeing" to participants, and described general wellbeing as being comprised of many facets of biological, mental, emotional, and relational health. While in some ways this definition could be seen as leading, it was critical to define wellbeing with some parameters in order to elicit responses related to such a holistic construct. No emphasis was made on the importance of different facets of general wellbeing, although the questions were designed to encourage participants to describe more facets of their psychosocial needs during the cancer experience.

The semi-structured interviews generally were completed between 45 and 90 minutes. During the interview, participants were asked to reflect upon their experiences during treatment via interview questions, as well as during the survivorship phase of their cancer journey. In line with CQR guidelines, the participants were asked several follow up questions or probes, to elicit the most specific picture of their experiences of wellbeing during the cancer experience (Hill, 2012). To protect anonymity, each participant was assigned a research participant code number (1-8) that was used to identity each interview.

Interview questions were developed based on existing literature, research recommendations from oncological professionals, feedback from dissertation committee members, and the research questions that guide this study. After the primary researcher received informed consent from each participant, the primary researcher emailed the participants the following interview questions:

1. How long have you been in remission (full or partial)?
2. What was your cancer diagnosis, and what kinds of treatments did you have?

3. When you consider your current wellbeing – as mentioned this can include physical, mental, spiritual, relational, etc. – how would you describe your current wellbeing?
4. How might what you are describing now be similar or different to your wellbeing while you were undergoing treatment? How is it similar or different to your wellbeing before you found out that you had cancer?
5. When you think about the impact cancer has had on you, how has it affected different aspects of your holistic wellness? What has been the most impactful physically? Emotionally? Mentally? Socially? As you reflect on your experience, what feelings come to mind?
6. What factors (personal, relational, communal, societal) have been the most helpful, supportive, or buffering for you during your experience with cancer? What factors (personal, relational, communal, societal) have been the most challenging?
7. Coping with cancer can include a lot of different resources such as having support from your family, receiving financial resources, or talking to your doctor about your experience. What was most important to you in coping with cancer early in your experience? During treatment? Now?
8. How did you feel, or do you currently feel, that your psychosocial (factors of wellbeing besides physical health) needs were supported throughout your experience? By your doctors and medical staff? By you caregivers? By any

other professionals you have been or are seeing related to your experience with cancer?

All semi-structured interviews were audio-recorded and transcribed verbatim. The researcher transferred interview audio recordings to a password-protected computer immediately after completing each interview. The primary researcher transcribed the audio recordings. After the interviews were transcribed, the digital recording was deleted from the digital recording device and the transcriptions were sent to the research team.

Data Analysis

Once the data was transcribed, it was analyzed using the CQR method. Data analysis begins with the coding of data into domains, which may be considered a list of topic areas that are discussed in the interviews (Hill, 2012). Before coding each transcript, a list of domains was generated (Hill, 2012). This study utilized an inductive approach to developing a domain list, which included the selection of two transcripts that were sent out to each research team member to code independently. This approach allows for a variety of perspectives and opinions, improves the complexity of the data, and is thought to reduce bias of any team member (Hill et al., 1997). Research team members went through the transcripts, blocked off particular topic areas and created a domain name for that topic area (e.g., Emotional Difficulties). Once each team member had created a domain list, the team met to compare notes and to work towards the creation of a consensual domain list that fits the needs of the study (Hill, 2012). The research team then added an addition interview to code using the new domain list, and continued to meet until they could agree upon a consensual domain list that fit the data.

The auditor was sent this list for review before the research team began to read the remaining interview transcripts. Following the domain list review and approval, the primary research coded domains for four of the remaining interviews, while the other two members took three interviews, thus insuring that each interview was coded by two research team members. Research team members independently assigned domains to their received transcripts. Research team members later met in dyads and worked on the domain codes until they were consensually coded. All material from the interviews were placed into a domain, although an "other" domain category was used for data that did fit in consensually created domains, but still seemed relevant to the study (Hill et al., 1997). Upon completion of coding the domains, all interviews were sent to the external auditor for review and suggestions. The research team reviewed the auditors suggestions related to domains and coded data within each case, and made adjustments as needed.

After the domains were coded, the primary research team began the process of creating core ideas (abstracts or brief summaries) and cross analyzing the data. In this step, research team members developed spreadsheets for each transcript, which included all transcript data, domains, and core ideas. The second and third research team members created spreadsheets for two of the transcripts, respectively, while the primary researcher created spreadsheets for the remaining four transcripts. The research team reviewed each spreadsheet one at a time to review core ideas and to suggest possible category/subcategory structures. Notably, the team agreed that one of the domains did not pertain to the research questions of the study, and was not included in the cross analysis.

Once a stable list of categories and subcategories for each domain emerged, the research team went back through each spreadsheet until consensus was reached for all categories, including their meaning, wording, and structure. Finalized spreadsheets were sent to the auditor for review, with descriptions of the category structures and proposed changes to the domain list. The auditor provided several suggestions for the team to review. The research team discussed the auditor's feedback and came to a consensus on how to incorporate the feedback into the final results.

Lastly, the primary researcher generated a master spreadsheet to include all domains and categories across transcripts, and applied frequency labels to each category and subcategory. Categories seen across all or all-but-one interviews (8-7) were designated as *general*, categories found in more than half (5-6) the cases were labeled as *typical*, and categories found in less than half of the cases (4-2) were labeled as *variant*. Any category present only in one case was labeled as rare (Hill, 2012; Hill et al., 1997).

Integrative Analysis

The last data analysis, answering research question four (Are current models consistent with the identified salient psychosocial factors in the lived experiences of cancer survivors?), was conducted by the primary researcher and integrated the quantitative data with the qualitative data and explore relationships between study findings. The goal of this analysis was to discuss how the qualitative findings might help explain the quantitative results, and additionally to highlight possible factors currently missing in wellbeing theoretical models used in medical and mental health disciplines.

Pilot Study

Introduction

Prior to conducting the main study noted above, a pilot study was conducted. The main objective of the pilot study was to obtain feedback on the methodology prior to administering the full study. Similar to the main study, the pilot study was implemented into two phases, with specific research questions for each phase. After receiving IRB approval the researcher implemented a pilot study.

Phase 1

The goals of the Phase 1 pilot study were to obtain feedback on (a) time estimates for completing the survey and (b) the format of the survey and clarity of items.

Research questions. The following research questions are exploratory in nature and were examined in the pilot study.

Research question 1: What is the estimated time for completing the online survey?

Research question 2: Are the survey items clear and relevant to the participants?

Research question 3: What improvements to the online survey do participants in the pilot study suggest?

Participants. Pilot study participants were recruited via word-of-mouth (snowball) sampling. As incentive to encourage participation, the primary researcher agreed to donate $1 for each completed survey to the LiveStrong Foundation, a charitable foundation that supports research, education, and support services for individuals who have experienced cancer (LiveStrong.org, 2015).

A sampling pool of 4 participants who met criteria for the full study was recruited. All of the participants were female (n =4), and ages ranged from 28 to 69, with the mean participant age being approximately 54 (SD = 18.41). The participants were predominantly white (n = 3), with the final participant identifying as "other." Participant cancer diagnosis included breast (n = 2), thyroid (n = 1), and melanoma (n = 1). Treatment categories among participants included surgery (n = 4), chemotherapy (n = 1), radiation (n = 1), and other (n = 1; tomoxifin).

Instrumentation. Consenting participants completed three standardized instruments and a demographic questionnaire, as described in the main study. At the end of each survey packet, three additional questions were provided to the pilot study participants:

1. How would you describe the clarity of the surveys and demographic form you completed?

2. Are there any specific items that did not seem relevant to your experience of wellbeing during cancer survivorship? If so, please indicate.

3. What improvements to the online survey would you recommend?

Procedures. After receiving IRB approval to proceed with the study, the researcher forwarded a link to the external study web page (Appendix A) to a few family members and friends, and requested that they forward this link to one or two possible participants. Prospective participants who visited the external web page saw a brief description of the study, the study criteria, and the link to the online survey packet. Participants who clicked on the survey link were taken to the first page of the Qualtrics

survey, which included an informed consent form (Appendix A). Individuals who elected to participate in the study were encouraged to print a copy of the informed consent for their records, as it outlines the purpose of the study, efforts made by the researcher to ensure confidentiality, potential risks of participation, and the voluntary nature of the study. Upon consent, participants were taken to a second section of the survey containing the CES-D-10 (Andersen et al., 1994), the FACT-G (Cella et al., 1993), and the FFWEL-A (Myers & Sweeney, 2005b). Instructions for completing each assessment were provided prior to assessment questions. At the end of the survey packet, participants answered three additional items as described in the instrumentation section.

Upon completion of the study, pilot study participants were asked to indicate (via "yes" or "no" checkbox) if they were interested in participating a subsequent interview discussing their perspective on their holistic wellbeing throughout their experience with cancer. Participants who checked "yes" were asked to provide an email address for further contact. Participants who clicked "no" then closed out of the survey. Individuals who elected to be considered for, and who were eventually contacted for the semi-structured interview were required to give additional consent in Phase 2 of the study.

Data analysis. The researcher reviewed findings and participant input as it related to pilot study research questions and considered modifications for clarity and organization to the main study.

Results of phase 1. Time estimates for completing the study (RQ1) were approximately 41 minutes, 63 minutes, 24 minutes, and 5400 minutes (90 hour), with a mean time of 1382 minutes (approx. 23 hours). In the case that the final completion time

estimate is an outlier, which will be discussed in the implications section, time estimates for completing the study ranged from 24-63 minutes, with a mean time of 43 minutes.

Pilot study participants feedback relevant to RQ2 (Are the survey items clear and relevant to the participants?), included pilot study questions related to the clarity of the items and the relevance of the survey items to participant experience of cancer survivorship. Participant responses supported the clarity of demographic and survey items, but two participants indicated uncertainty if responses to the surveys should match their current experiences in survivorship or their experiences during treatment. Responses to a pilot study question regarding the relevance of questions were varied. Two participants noted a lack of relevance with items in the FFWEL, with one participant citing lack of relevance of questions around male/female identity (items #6, #22, #45, #57, gender identity scale), and another citing confusion with the question "Do you look forward to getting older?" (item #89). One participant indicated that all items seemed relevant. The final participant cited that several questions were not relevant, but did not provide specific examples.

The final question solicited information on how to improve the study. One participant indicated that two answers to questions should be allowed so that participants could respond according to length of time from diagnosis (e.g., "1 year after diagnosis, and then 2 or 3 years after diagnosis"). Similar feedback was given by an additional respondent that suggested questions be different for individuals still fighting cancer and individuals who have "survived cancer" (likely meaning those who are in full remission). One participant, who identified as retired, suggested the inclusion of "not applicable" for

questions in the FFWEL that refer to work or school. The final participant noted that some questions seemed to refer to general personality traits, and questioned how these items related to cancer survivorship.

Phase 2

The goals of the Phase 2 pilot study were to obtain feedback on the relevance and wording of semi-structured interview questions and time estimates for completing the semi-structured interview.

Research questions. The following questions are exploratory in nature and wereexamined in the pilot study.

Research question 1: What is the estimated time for completing the semi-structured interview?

Research question 2: Are proposed semi-structured interview questions for Phase 2 of the main study relevant and clear?

Research question 3: What improvements to the semi-structured interview does the pilot study participant suggest?

Participants. The participant for Phase 2 was recruited from the pilot study participants in Phase 1 who elected to be considered for the semi-structured interview, and therefore met all participant requirements previously mentioned. The participant was a White non-Hispanic female, age 55, with a history of melanoma.

Procedures. Three participants from Phase 1 consented to be considered for Phase 2, and provided an email address. The primary researcher contacted participants one at a time, and waited a week for a response before contacting the next participant on

the list. The researcher sent out reminder emails to all participants after establishing initial contact with all three participants, and received a response from the final participant contacted after a reminder email was sent. The primary researcher provided the Phase 2 pilot study participant with a consent form via email. Once the participant returned the consent form, the researcher sent the participant the list of interview questions utilized in the semi-structured interview. As the participant was asked to reflect upon their experiences over a time span of up to five years, providing the questions in advance was appropriate, as it allowed time for the participant to reflect upon their experiences. The researcher and participant also agreed upon a scheduled time for completing the interview. As incentive to participate, the pilot study participant was given a $10 gift card to their choice of Target, Panera, or Starbucks within a week of completing the scheduled semi-structured interview.

During the scheduled interview time, the primary researcher called the participant over the phone and recorded the conversations using a recording device. As QoL and wellness are discipline-specific concepts, the primary researcher also gave a brief description of "holistic wellbeing" to the participant, and described holistic wellbeing as being comprised of many facets of biological, mental, emotional, existential/spiritual, and social health. No emphasis was made on the importance of different facets of general wellbeing, although the questions were designed to elicit participant responses that described more facets of their psychosocial needs during the cancer experience. In line with CQR guidelines, the participant was asked several follow up questions or probes, to

elicit the most specific picture of their experiences of wellbeing during the cancer experience (Hill, 2012).

The following interview questions were developed based on existing literature, research recommendations from oncological professionals, feedback from dissertation committee members, and the research questions that guide this study:

1. How long have you been in remission (full or partial)?
2. What was your cancer diagnosis, and what kinds of treatments did you have?
3. When you consider your current wellbeing – as mentioned this can include physical, mental, spiritual, relational, etc. – how would you describe your current wellbeing?
4. How might what you are describing now be similar or different to your wellbeing while you were undergoing treatment? How is it similar or different to your wellbeing before you found out that you had cancer?
5. When you think about the impact cancer has had on you, how has it affected different aspects of your holistic wellness? What has been the most impactful physically? Emotionally? Mentally? Socially? As you reflect on your experience, what feelings come to mind?
6. What factors (personal, relational, communal, societal) have been the most helpful, supportive, or buffering for you during your experience with cancer? What factors (personal, relational, communal, societal) have been the most challenging?

7. Coping with cancer can include a lot of different resources such as having support from your family, receiving financial resources, or talking to your doctor about your experience. What was most important to you in coping with cancer early in your experience? During treatment? Now?
8. How did you feel, or do you currently feel, that your psychosocial (factors of wellbeing besides physical health) needs were supported throughout your experience? By your doctors and medical staff? By you caregivers? By any other professionals you have been or are seeing related to your experience with cancer?

In addition to the core semi-structured interview questions, the participant in the pilot study was asked the following questions to gain information relevant to the pilot study research questions:

1. How would you describe the clarity and relevance of the interview questions?
2. Are there any questions that did not make sense?
3. What improvements to the semi-structured interview would you recommend?

Data analysis. The researcher reviewed participant input as it related to pilot study research questions and considered modifications for clarity and organization to the main study.

Results of phase 2. The semi-structured interview took approximately an hour to complete, with an additional ten minutes added to discuss pilot study questions. When asked about the clarity and relevance of the interview questions, the participant indicated that all of the items seemed relevant and clear. Several questions elicited responses that

corresponded with other questions (e.g., responses about lack of support from medical professionals was discussed in question 4, but is directly asked about in question 8). The participant and researcher felt that the nature of the questions lent themselves to this type of reflexivity. However, question 6 "What factors have been most helpful…." seemed unnecessary in the interview, as responses to other several questions (particularly questions 5 and 7) included factors relevant to that question. The researcher probed to ask about the usefulness of examples given (e.g., What has been most helpful physical? Emotionally?) that add length to the questions. The participant shared that the questions could be shortened in some cases, but stressed that examples were helpful for the participant in thinking about her answers in advance. The researcher similarly noted that through the interview, some of the questions could have been shortened while retaining the content.

The participant also gave suggestions for improving the study. At the beginning of the interview, the participant commented that she "hope [her] responses were what the research was looking for," to which the researcher responded "you as the participant defines what is important." The participant noted that it was "hugely helpful" to know that her perspective was important, and suggested clarifying the importance of the participant perspective at the beginning of each interview to reduce social desirability bias. The participant also indicated that sharing the semi-structured interview questions in advance was helpful in considering her responses.

Limitations

The small number of participants limits the result of the pilot study. All the participants were female. Although the study included one participant who was under 30 and identified as non-white, three of the four participants were fairly homogenous being white and 55 or older. The small sample size may also be a limitation in predicting estimated time for completing the larger study. Additionally, there may be other possible modifications that would improve the study not identified by the sample due to their homogenous nature.

Implications

Based on results from the pilot study, several modifications to the study are implicated. The pilot study findings from Phase 1 implicated an increase in estimated time for the survey portion of the study, as well as clarification on time-of-reference for completing the surveys in the study description provided in the study consent form. Implicated modifications for Phase 2 include simplification of interview questions, as well as modifications to recruitment communication to include a time window for scheduling participant interviews. The following sections highlight these modifications in greater detail.

Phase 1 implications. The original time estimate given for Phase 1 pre-pilot study was 20-40 minutes. Results from Phase 1 RQ1 (What is the estimated time for completing the online survey?) included a broader range of times from 23-5400 minutes. However, it is likely that the final participant time estimate of 5400 minutes (90 hours) is an outlier time, as the Qualtrics platform allows participants to keep their browser open

for extended amounts of time. It would be unrealistic for survey completion times to last several days. Excluding this time point, it is reasonable to suggest that completion times for Phase 1 range from 25-60 minutes. This time range goes beyond the original hypothesized time of 20-40 minutes, and should be modified in Phase 1 recruitment documents.

Results from Phase 1 RQ2 (Are the survey items clear and relevant to the participants?) were mixed, and varied in terms of applicability. While one participant endorsed that some items were not relevant, they did not provide specific examples. At least one participant suggested that all items were relevant. Two participants noted a perceived lack of relevance with questions in the FFWEL that relate to gender identity and a desire to grow older. However, removing these questions from the FFWEL would threaten the integrity of the entire instrument. Additionally, while questions related to gender or identity or a desire to grow older may not apply to the pilot study participants, both factors have shown relevant in oncological research. For example, gender identity has been shown to be a significant factor in distress among transgender cancer survivors (Kamen, Mustian, Dozier, Bowen, & Li, 2015). A desire to continue living, which is inversely impacted by the presence of significant symptoms of depression, has also been found to be relevant to cancer survivors' prognosis and utilization of care (Breitbart et al., 2000). Two participants indicated feeling uncertain if there responses should correlate with their current experiences or their experiences while undergoing cancer treatment. Although each assessment includes directions to respond to questions from present

experience, the primary researcher will highlight that participants should respond to all questions according to their current experiences.

Responses to the final Phase 1 research question (What improvements to the online survey would you recommend?) provided additional feedback for consideration in the main study. One participant indicated that the study could be improved by giving multiple answers to each question that would correspond with length of time from diagnosis (e.g., 1 year after diagnosis, and then 2 or 3 years after diagnosis"). Clarification around the desired time point for this study (the participant's present experiences) may highlight that the study is cross-sectional and is not intended to capture multiple time points of data. Another participant suggested different studies for individuals who have survived cancer (full remission), or who are in partial remission; this feedback may also support further investigation of wellbeing at multiple stages of the cancer journey. Furthermore this study utilizes the Centers for Disease Control definition of cancer survivorship, which includes any individual who has been diagnosed with cancer, from the time of diagnosis for the rest of their life (Centers for Disease Control and Prevention, 2016a). Additionally, the study criteria specifically state that it includes individuals in both full and partial remission. Another participant suggested removing questions related to personality traits. Removal of these questions would threaten the integrity of the instruments; moreover personality traits have been directly tied to coping strategies that predict wellbeing among cancer survivors (e.g., Dahl, 2010; Saita, Acquati, & Kayser, 2015). The final participant suggested the availability of a N/A response for items relating to work or school, as several of the participants are likely to be retired.

Phase 2 implications. Modifications of phase two include edits to several of the questions, and the exclusion of question six due to redundancy in responses. The remaining questions were streamlined to stay as close to the content as possible, while others were split to improve clarity (e.g., question 4 *"How might what you are describing now be similar or different to your wellbeing while you were undergoing treatment? How is it similar or different to your wellbeing before you found out that you had cancer?"* was split into two questions to provide more accurate responses). As suggested during pilot study feedback, the original question six was eliminated due to redundancy. The revised questions are as follows:

1. How long have you been in remission (full or partial)?
2. What was your cancer diagnosis, and what kinds of treatments did you have?
3. Consider the different aspects of your wellbeing: physical, mental, spiritual, relational, etc. – how would you describe your current wellbeing in these areas?
4. How is your current wellbeing similar or different to your wellbeing while you were undergoing treatment?
5. How is your current wellbeing similar or different to your wellbeing before you found out that you had cancer?
6. When you think about the impact cancer has had on you, how has it affected different aspects of your holistic wellness? These aspects include your physical, mental, social, and spiritual wellness.

7. Coping with cancer can include many different resources such as having support from your family, receiving financial resources, or talking to your doctor about your experience. What types of resources have been important to you in your cancer journey?

8. How did you feel, or do you currently feel, that your psychosocial (non-biomedical) needs were supported throughout your experience? Sources of support may include medical staff, caregivers, friends, and any other professionals you saw related to your experience with cancer.

Additionally, some changes to recruitment for Phase 2 may be beneficial. In the pilot study, three out of four participants in Phase 1 agreed to be considered for Phase 2, but only one participant responded when the primary researcher contacted them via the provided email address. After discussion with dissertation co-chairs, the primary researcher edited the recruitment question in Phase 1 for Phase 2 to include: "Interviews will take place in the next 2-3 weeks." The pilot study participant also highlighted the significance of stating that participants define factors that are important, rather than answering questions according to the values of the researcher. The primary researcher will highlight the importance of participant perspectives in Phase 2 in the main study by including this statement in the second consent form.

Conclusion

The pilot study demonstrated that the bulk of the study questions appear relevant to cancer survivors in relation to their psychosocial wellbeing. Modest modifications were made to improve the clarity and relevance of study questions for participants.

Further research on factors of psychosocial wellbeing has the opportunity to provide information about how to best assess and support cancer survivors in their psychosocial needs. These findings may be relevant to medical care providers as well as mental health professionals.

CHAPTER IV

RESULTS

Introduction

In order to examine and identify the significant psychosocial needs of cancer survivors, this study utilized a sequential explanatory mixed methods study design. The following chapter provides the results of the quantitative and qualitative analysis implemented to address the hypotheses presented in the previous chapters. This chapter is organized in three sections. The first section will provide an overview of the quantitative portion, including a description of the sample characteristics followed by the quantitative data analysis results. The second section will provide an overview of the qualitative results and sampling information obtained in the qualitative portion. The third section will provided a brief summary of the integrated analysis.

Phase 1: Quantitative Methodology

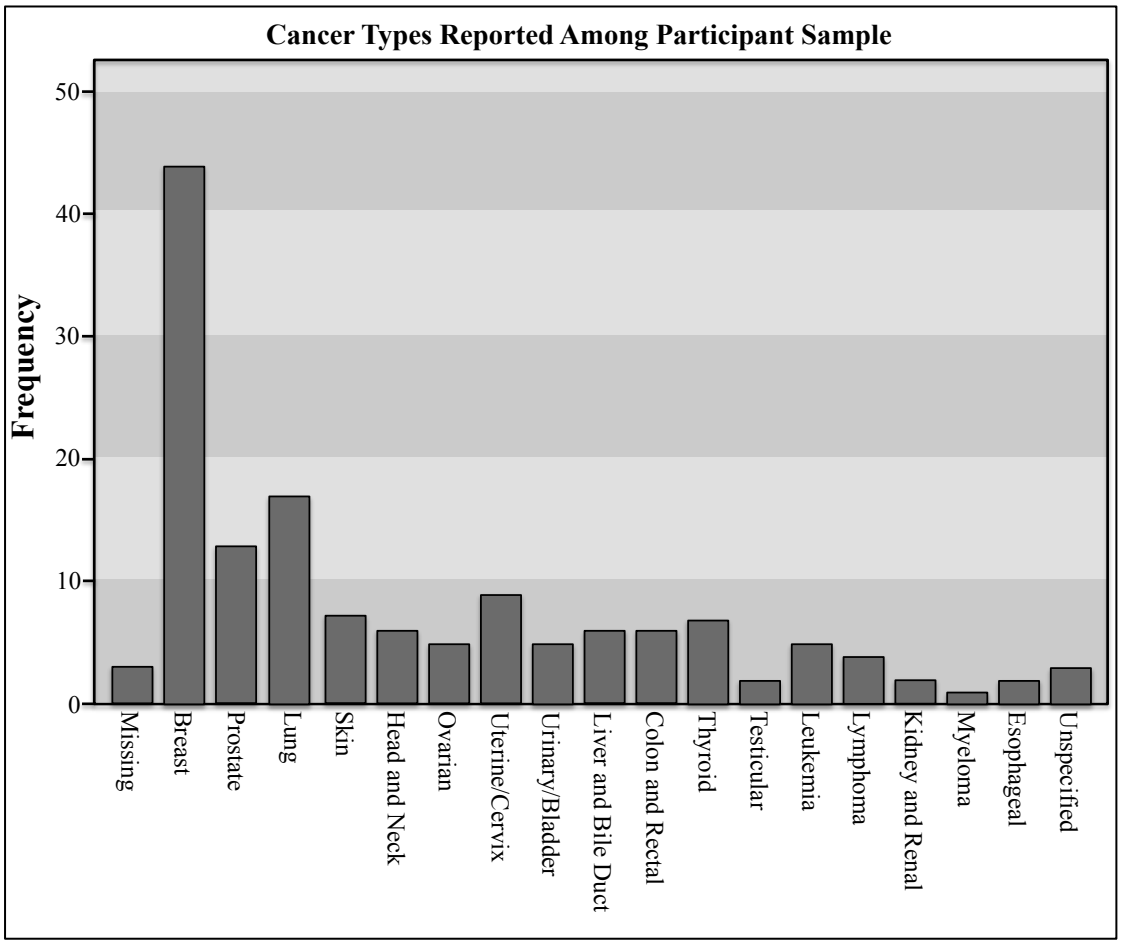
Description of Sample

One hundred and forty-seven cancer survivors participated in Phase 1. The majority of participants were female (n = 107, 72.8%), with the remainder being male (n = 40, 27.2%). Age at the time of study completion ranged from 18 to 91, with a mean age of 49.25 years (SD = 14.9), median age of 50.5 years, and mode age of 43 years. Relative to race, 81% of the sample identified as White (n = 119), 6.8% identified as Black (n = 10), 6.8% identified as Hispanic (n = 10), 2.7% identified as Asian/Pacific Islander

(n = 4), 1.4% identified as American Indian/Alaskan Native (n = 2), 0.7% identified as "other" (n = 1), and one participant endorsed the option "Prefer not to answer".

Participants reported various cancer types, remission statuses, stages, and treatment categories. Six participants did not disclose their type of cancer (but provided additional details of their cancer experience such as treatments, date of diagnosis, etc.); thus, of the participants who disclosed their cancer type (n = 141), 17 cancer types were indicated within the participant sample (Figure 2). The most common diagnoses reported include cancers of the breast (n = 44, 29.9%), lung (n = 17, 11.6%), and prostate (n = 13, 8.8%). The majority of participants reported being in full remission (n = 106, 72.1%), with the remainder reporting partial remission (n = 41, 27.9%). In cancer staging, 56 participants reported a cancer diagnosis at Stage I (38.1%), 46 participants reported a cancer diagnosis at Stage II (31.3%), 30 participants reported a cancer diagnosis at Stage III (20.4), 14 participants reported a cancer diagnosis at Stage IV (9.5%), and one participant chose not to disclose their cancer staging (.7%). Reported cancer treatments received varied among participants; 116 participants reported receiving surgical treatment (78.9%), 73 participants report receiving chemotherapy (49.6%), 93 participants reported receiving radiation (63.3%), and 17 participants reported receiving additional adjuvant therapies (11.6%). It is important to note that many participants endorsed receiving multiple types of treatments.

Figure 2. Frequency of Participant Cancer Types



Data Analysis

Prior to conducting the multiple regressions, the relevant assumptions of this statistical analysis were tested. In assessing for multicollinearity, a correlation matrix (see Table 2) reveal significant correlations ($p < .05$) between all explanatory variables, and the independent variable of depression, besides the QoL FACT-G Physical Wellbeing scale with both the wellness FFWEL-A Essential Self and FFWEL-A Physical Self scales. However, all tolerance and VIF (variance inflation factor) statistics fall within the

normal range (tolerance > .20, VIF < 5), which indicates that the model does not have significant multicollinearity. For reference of these values, see Table 3.

Table 2

Pearson Correlations Between Variables (*N = 147*)

	1	2	3	4	5	6	7	8	9	10
1. CESD.10	1.000									
2. FACT-G PWB	-.663*	1.000								
3. FACT-G SWB	-.562*	.231*	1.000							
4. FACT-G EWB	-.697*	.750*	.391*	1.000						
5. FACT-G FWB	-.628*	.516*	.528*	.545*	1.000					
6. FFWEL-A SOC	-.517*	.215*	.751*	.287*	.444*	1.000				
7. FFWEL-A CRTV	-.579*	.237*	.607*	.259*	.577*	.687*	1.000			
8. FFWEL-A ESS	-.385*	.112	.450*	.162*	.415*	.472*	.641*	1.000		
9. FFWEL-A PHY	-.388*	.124	.463*	.144*	.399*	.487*	.654*	.551*	1.000	
10. FFWEL-A COP	-.664*	.335*	.570*	.436*	.591*	.540*	.777*	.513*	.585*	1.000

Note 1: PWB = Physical Wellbeing; SWB = Social Wellbeing; EWB = Emotional Wellbeing; FWB = Functional Wellbeing; COP = Coping Self; CRTV = Creative Self; ESS = Essential Self; PHY = Physical Self
*Note 2: * $p < .05$*

Table 3

Collinearity Statistics

	Tolerance	VIF
FACT-G PWB	.397	2.517
FACT-G SWB	.355	2.819
FACT-G EWB	.344	2.907
FACT-G FWB	.452	2.213
FFWEL-A SOC	.341	2.935
FFWEL-A CRTV	.222	4.497
FFWEL-A ESS	.549	1.821
FFWEL-A PHY	.518	1.930
FFWEL-A COP	.315	3.170

Note 1: PWB = Physical Wellbeing; SWB = Social Wellbeing; EWB = Emotional Wellbeing; FWB = Functional Wellbeing; COP = Coping Self; CRTV = Creative Self; ESS = Essential Self; PHY = Physical Self

The researcher also examined the skewness and kurtosis to evaluate the normality of the distribution. The range of normal skewness (which characterizes the degree of asymmetry of distribution around the mean) is considered to be twice the standard error of skewness (0.200, normal range = $\pm$0.400). In this sample, all but three of the wellbeing scales (scales in the FACT-G and FFWEL-A) have a negative skew, with normal distributions in the FACT-G Functional Wellbeing scale, the FFWEL-A Essential Self scale, and the FFWEL-A Physical Self scale, respectively. The skewness of total scores for the FACT-G and the FFWEL-A are similarly skewed negatively, indicating a trend towards higher wellbeing scores. The CES-D-10 has a positive skew, indicating a trend towards higher depression scores. In the current sample, 57.1% of participants met the cut-off of a score of 10 or higher on the CES-D-10, which indicates the presence of significant depressive symptomology. The range of normal kurtosis (the relative peakness or flatness of the distribution) is similarly twice the standard error of kurtosis (0.397, normal range = $\pm$0.794). In evaluating for kurtosis, three wellbeing scales of the

FFWEL-A demonstrated a leptokurtic distribution, with scores concentrated around the mean: the Coping Self, the Creative Self, and the Social Self. Notably, although the distribution of data in several cases violated assumptions of normality, such violations are only problematic when testing norm-population references (Brown, 1997). In the case of these data, scores that indicated below-average wellbeing and above-average rates of depression were consistent with researcher findings on cancer survivors. For these and other statistics, please refer to Table 4.

Table 4

Distribution Statistics

	Mean	Std. Dev	Skewness	Kurtosis
FACT-G PWB	17.912	7.435	-0.719*	-0.338
FACT-G SWB	19.332	6.858	-0.886*	0.109
FACT-G EWB	15.306	5.976	-.546*	-0.574
FACT-G FWB	16.640	6.458	-0.236	-0.794
FACT-G TOTAL	69.189	20.987	-0.493*	-0.153
FFWEL-A COP	71.482	10.886	-0.631*	1.045*
FFWEL-A CRTV	76.223	11.260	-0.839*	2.376*
FFWEL-A ESS	77.764	11.103	-0.321	-0.354
FFWEL-A PHY	69.133	16.119	-0.247	-0.525
FFWEL-A SOC	83.440	14.678	-1.228*	1.785*
FFWEL-A TOTAL	74.922	10.003	-0.606*	0.563
CES-D-10	11.7075	6.892	0.584*	-0.163

Note 1: PWB = Physical Wellbeing; SWB = Social Wellbeing; EWB = Emotional Wellbeing; FWB = Functional Wellbeing; COP = Coping Self; CRTV = Creative Self; ESS = Essential Self; PHY = Physical Self
*Note 2: * indicates non-normality of the distribution*

The first research question explored the extent to which the medical wellbeing model of QoL (operationalized by the FACT-G second-order subscales) and the counseling wellbeing model of wellness (operationalized by the FFWEL-A second order subscales) accounted for variance in depression scores. To determine the influence of these factors, a series of forced-entry multiple regressions were computed with depression as the dependent variable and the QoL model predictors and wellness model predictors as the independent variables, respectively. As the primary researcher has also described possible links between these models, an additional two-step hierarchical method was computed in order to more closely examine multicollinearity between QoL and wellness in their abilities to predict depression scores.

In order to determine the amount of variance in depression by each model, the researcher initially performed two sets of multiple regressions. In the first multiple regression, the QoL model predictors, or FACT-G second order subscales, were entered as independent variables for predicting depression score. The regression model was significant (F (4, 142) = 69.007, $p < .000$; $R^2 = .661$), explaining 66% of the variance in depression scores. A post hoc analysis was computed with a large effect size (Cohen's f^2 = 1.949). As hypothesized, all QoL predictors in the model were significant ($p < .05$) and negatively related to depression (see Table 5). In the second multiple regression, wellness model predictors, or the FFWEL-A second order subscales, were entered as independent variables for predicting depression scores. In this analysis, wellness model predictors were found to account for 48% of variance in depression scores (R^2 =.480), and a significant regression equation was found (F(5, 141) = 25.994, p < .000). A post

hoc analysis was computed with a large effect size (Cohen's f^2 = .923). However, results showed that only two predictors significantly impacted depression scores. These included the Social Self and Coping Self subscales, which were both negatively related. The Creative Self, Essential Self, and Physical Self were not statistically significant in relation to depression (see Table 6).

Table 5

Regression Analysis for QoL (FACT-G second order subscales)

	B	***SE***	***β***	***t***	**sig.**
FACT-G PWB	-.300	.071	-.323	-4.205	.000
FACT-G SWB	-.305	.060	-.303	-5.102	.000
FACT-G EWB	-.282	.091	-.244	-3.080	.000
FACT-G FWB	-.179	.071	-.168	-2.537	.012

Note 1: PWB = Physical Wellbeing; SWB = Social Wellbeing; EWB = Emotional Wellbeing; FWB = Functional Wellbeing

Table 6

Regression Analysis for Wellness (FFWEL-A second order subscales)

	B	***SE***	***β***	***t***	**sig.**
FFWEL-A SOC	-.105	.039	-.244	-2.668	.009
FFWEL-A CRTV	-.023	.076	-.038	-.303	.762
FFWEL-A ESS	-.008	.051	-.014	-.167	.868
FFWEL-A PHY	.032	.036	.075	.896	.372
FFWEL-A COP	-.349	.062	-.551	-5.637	.000

Note 1: COP = Coping Self; CRTV = Creative Self; ESS = Essential Self; PHY = Physical Self

Based on these analyses, the researcher concluded that the QoL assessment model (specifically, the FACT-G) accounted for more variance in depression scores than the wellness assessment model (the FFWEL-A). The hypothesis that the wellness model would explain more variance than QoL was not supported.

The second research question was intended to identify the shared and uniquevariance each model of wellbeing contributed to predicting depression scores. As noted from the initial two regression models from research question 1, in isolation, QoL explained more variance than the FFWEL-A. However, a third regression was conducted to examine the amount of overlap between the multidisciplinary models of wellbeing. To conduct the analysis, the researcher ran a third multiple regression entering all QoL and FFWEL-A subscales in a two-step hierarchical method. A two-step method was necessary for this analysis in order to compare the subscales of the QoL and wellness models as two distinct sets of predictors. QoL model predictors (FACT-G second-order subscales) were entered into the first step of the hierarchical multiple regression. In the second step, wellness model predictors (FFWEL-A second order subscales) were entered. In the first step, as previously reported, QoL model predictors accounted for 66% of variance in depression scores (R^2= .661). In the first regression model, all predictors were found to be significant. In the second step, when wellness model predictors were added, the multiple regression model accounted for additional variance (R^2 change = .066) after controlling for variance explained by QoL model predictors. The full model was significant (F(9, 137) = 40.543, p<.000), indicating that together, QoL and wellness models accounted for 73% of variance in depression scores (R^2= .727). A post hoc

analysis was computed with a large effect size (Cohen's $f^2 = 2.663$). In the second model, only two of the four predictors entered in step 1 were found to be significant (FACT-G Physical and Emotional Wellbeing respectively), while the FACT-G Functional Wellbeing and Social Wellbeing scales were shown to no longer contribute significantly to the model. Of the additional predictors entered, only the FFWEL-A Coping Self was found to significantly contribute to the model, while the Social Self, Physical Self, Essential Self, and the Creative Self did not significantly contribute to the regression model. For these and other statistics of the two-step hierarchical regression analysis, refer to Table 7.

Table 7

Two-Step Hierarchical Regression Analysis for Depression Scores

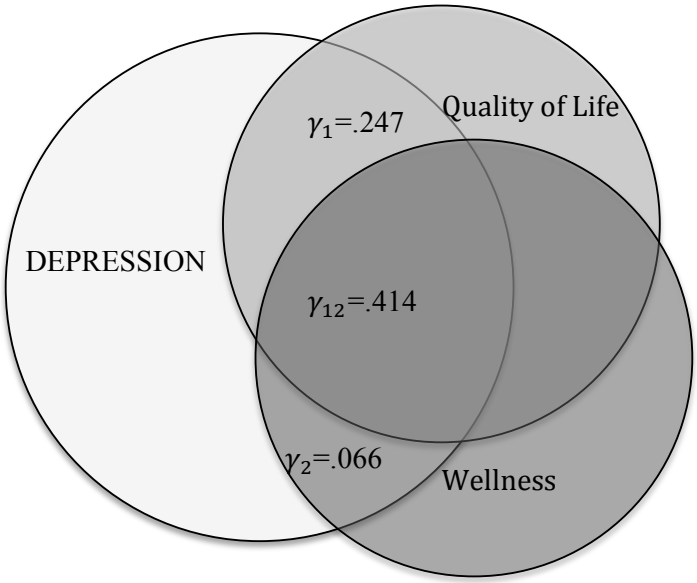
	R^2	ΔR^2	*B*	*SE*	β	*t*	Sig.
Model 1	.661						
FACT-G PWB			-.300	.071	-.323	-4.205	.000
FACT-G SWB			-.305	.060	-.303	-5.102	.000
FACT-G EWB			-.282	.091	-.244	-3.080	.002
FACT-G FWB			-.179	.071	-.168	-2.537	.012
Model 2	.727	.066					
FACT-G PWB			-.295	.066	-.318	-4.490	.000
FACT-G SWB			-.122	.075	-.122	-1.624	.107
FACT-G EWB			-.279	.088	-.242	-3.184	.002
FACT-G FWB			-.029	.071	-.027	-.410	.682
FFWEL-A COP			-.150	.050	-.236	-2.976	.003

FFWEL-A CRTV	-.072	.058	-.117	-1.241	.217
FFWEL-A ESS	-.015	.037	-.025	-.410	.682
FFWEL-A PHY	.005	.027	.012	.194	.836
FFWEL-A SOC	-.029	.036	-.062	-.805	.422

Note: PWB = Physical Wellbeing; SWB = Social Wellbeing; EWB = Emotional Wellbeing; FWB = Functional Wellbeing; COP = Coping Self; CRTV = Creative Self; ESS = Essential Self; PHY = Physical Self

To calculate the unique versus shared variance of each wellbeing model, a commonality analysis was conducted (Nimon, 2010). Commonality analysis consists of subtracting the R^2 of the first set of multiple regression analysis (QoL $R^2 = .661$; Wellness $R^2 = .480$) from the R^2 of the full two-step hierarchical regression ($R^2 = .727$). To find the common effect, or the shared variance between each model, the R^2 from each singular model is added (QoL + wellness R^2), and then the R^2 from the two-step model is subtracted from this value. Figure 3 depicts the relationship between each model in explaining variance in depression scores, as well as the shared and unique contribution of each model.

Figure 3. Commonality Analysis of Wellbeing Models and Depression



Total $R^2 = R^2_{.12} = .727$
FACTG $R^2 = R^2_{.1} = .661$
FWEL $R^2 = R^2_{.2} = .480$

Unique Variance of FACTG= $R^2_{.12} - R^2_{.2}$ = (.727) – (.480)= .247 (=γ_1)
Unique Variance of FWEL= $R^2_{.12} - R^2_{.1}$ = (.727) – (.661)= .066 (=γ_2)
Common Effect of FACT and FWEL= $R^2_{.1} + R^2_{.2} - R^2_{.12}$ = (.661) + (.480) – (.727) = 0.414 (=γ_{12})

These findings indicate that the QoL model contributes more unique variance than the wellness model to depression scores; however, QoL and wellness have more shared variance than unique variance in explaining depression scores. These findings support the hypothesis that QoL and wellness models of wellbeing have more shared than unique variance.

Phase 2: Qualitative Methodology

The second phase of the study was designed to answer the third research question: What do cancer survivors perceive as salient psychosocial needs or factors currently and previously in treatment? In order to answer this question, consensual qualitative research

methodology (CQR) was utilized (CQR; Hill, Thompson, &Williams, 1997). As described in chapter three, the second phase of the study consisted of eight semi-structured interviews of cancer survivors around their psychosocial experiences and needs. Notably, since this study was built upon a theoretical orientation of holistic wellbeing, interview questions were designed to explore the complex relationships therein and included content related to mental, emotional, social, physical, and functional wellbeing. To complete the analysis, the interviews were conducted and transcribed by the primary researcher. A research team, including an external auditor, analyzed the interviews and consensually coded the data into meaningful domains and categories.

Description of Sample

Participants for Phase 2 of this study included eight cancer survivors who were recruited through convenience sampling from Phase 1 participants. Three of the eight participants were male, and five were female. Seven participants identified their race/ethnicity as White, and one identified as Hispanic. Ages of participants ranged from 43 to 70, with a mean age of 54.9 (SD = 9.8). Among participants, four reported having breast cancer (Stage I: n = 3; Stage II: n = 1), one reported having cholangiocarcinoma (bile duct cancer; Stage I), one reported having rectal cancer (Stage III), one reported having prostate cancer (Stage III), and one participant reported having uterine cancer (Stage III). Participants reported experience with a variety of cancer treatments, including surgery (n = 7), chemotherapy (n = 2), radiation (n = 4), and adjuvant therapies (herceptin; n = 1).

Additionally, participants in phase 2 demonstrated a range of scores on the assessment scales explored in phase 1. QoL scores, as measured by the FACT-G total score (Cella et al., 1993), ranged from 57 to 103, with an average score of 82 among participants (*SD* = 19.5) (*FACT-G score range 0-108*). Wellness scores, as measured by the FFWEL-A total score (Myers & Sweeney, 2005b), ranged from 64 to 87.1 with a mean score of 77.6 among participants (*SD* = 7.1) (*FFWEL-A total score range 25-100*). Notably, both the FACT-G and the FFWEL-A total scores are interpreted somewhat subjectively, with higher scores indicating higher levels of wellbeing, and lower scores indicating lower levels of wellbeing. Additionally, depression scores, as measured by the CES-D-10 (Andersen, Malmgren, Carter, & Patrick, 1994), ranged from 2 to 19, with a mean score of 9.1 among participants (*SD* = 6.1). The CES-D-10 has a score range of 0-30, with scores of 10 or higher indicating the presence of significant depressive symptomology (Andersen et al., 1994). Three of the eight participants (*37.5%)* met the cutoff for significant depressive symptomology.

Summary of Findings

Analysis of the eight qualitative interviews resulted in the development of seven domains including a domain of "other" for relevant data that did not fit into the other domains. The following domains were developed to describe the wellbeing experiences of cancer survivors: (1) experience with healthcare professionals and settings, (2) physical and functional wellbeing, (3) external supports and resources, (4) psychosocial coping strategies, (5) impact of cancer on psychosocial wellbeing, (6) cancer profile, and (7) other. The definitions of each domain can be found below in Table 8.

Further analysis of the domains resulted in the creation of categories, and in several cases subcategories, within each domain across all cases. Notably, during the cross analysis, the research team consensually agreed to omit the "cancer profile" domain from further analysis, as the data did not pertain directly to the research question for the study, and was essentially a duplication of sampling data. Table 9 is a visual representation of the domains, categories, and variance labels across the eight cases analyzed. In this study, a label of *general* was assigned to categories found within 7-8 cases, a label of *typical* was assigned to categories found within 5-6 cases, and a label of *variant* was assigned to categories found within 2-4 cases. Categories found within a singular case were labeled *rare*.

Table 8

Domain Definitions

Domain Title	Definition
Experience with healthcare professionals and settings	Narrative or reflection that discusses a participant's interactions and reactions to health care professionals, which may include doctors, nurses, social workers, mental health providers, genetic counselors, or general health care settings.
Physical and functional wellbeing	Any discussion of physical or functional ability that relates to the participants current wellbeing or their wellbeing during treatment.
External supports and resources	External supports utilized, or mentioned as a need, a barrier, or an unavailable support that the participant feels may have been useful. These may include psychosocial, instrumental, and informational supports and resources.
Psychosocial coping strategies	Internal resources and strategies utilized to help the participant cope with their cancer experience at any point on their cancer journey.
Impact of cancer on psychosocial wellbeing	Any psychosocial changes or impacts that came about as a result of specifically experiencing cancer. These may include mental, emotional, and social impacts.
Cancer profile*	Descriptions of the cancer diagnosis, prognosis information, and treatment.
Other	Relevant items that do not fit within other identified domains.

Note: Data coded under the domain of "cancer profile" was omitted from further analysis*

Table 9

Domains, Categories, Subcategories, Participants, and Frequency Labels

Domains	Categories and Subcategories	Participants	Label
Experience With Healthcare Professionals and Settings	Positive care experiences.	1,2,3,4,5,6,7,8	General
	Satisfaction with healthcare/treatment.	1,2,3,4,5,6,7	General
	Receipt of positive psychosocial support.	2,3,4,5,6,7,8	General
	Appreciation for informational support from healthcare professionals.	2,3,4,5,6,7	Typical
	Appreciation for healthcare setting/system.	5	Rare
	Negative care experiences.	1,4,5,7,8	Typical
	Dissatisfaction with healthcare/treatment.	1,4,5,7,8	Typical
	Lack of psychosocial support.	1,8	Variant
	Need for additional information and resources.	8	Rare
	Discomfort or dissatisfaction with healthcare setting/system.	1,4	Variant
	Other: Doctor has unpleasant personality.	2	Rare
	Other: Positive experience with insurance company.	7	Rare
Physical and Functional Wellbeing	Lasting negative impact on physical functioning.	1,2,6,7,8	Typical
	Negative impact to physical and functional wellbeing during treatment.	3,6,8	Variant
	Feelings of loss related to changes in abilities.	2,3,6	Variant
	Increase in positive health behaviors.	2,4,5,6,8	Typical
	Satisfaction with current physical and functional wellbeing.	3,4,5	Variant
External Supports and Resources	Social support.	1,2,3,4,5,6,7,8	General
	Social support from family and friends.	1,2,3,4,5,6,7,8	General
	Social support from spiritual community.	1,8	Variant
	Connecting with other cancer survivors.	1,8	Variant

	Social support from online cancer support groups.	8	Rare
	Instrumental Supports.	1,2,3,4,5,6,7,8	General
	Instrumental support from family and friends.	1,2,3,5,6,8	Typical
	Financial assistance from outside resources.	1,8	Variant
	Financial stability.	1,2,6,7	Variant
	Choice of treatment facility/options.	1,8	Variant
	Transportation assistance from outside resources.	1	Rare
	Cosmetic resources.	8	Rare
	Instrumental Support from Workplace.	4	Rare
	Informational Supports.	1,2,3,7	Variant
	From cancer support group web pages.	1,3	Variant
	From cancer foundation resources.	1,3	Variant
	From family and friends.	2,7	Variant
	Obstacles and Unmet Needs.	1,2,3,4,5,7,8	General
	Financial burden associated with cancer.	1,2,3,5,7,8	Typical
	Access to care.	1,2,4,8	Variant
	Scarcity of resources and information.	1,2	Variant
	Need for supportive follow-up care.	1	Rare
	Desire for increased societal awareness of cancer and it's effects.	2	Rare
	Limited or no social support.	5	Rare
	Other: experiential activities through cancer organizations.	8	Rare
Psychosocial Coping Strategies	Problem focused coping.	1,2,3,4,5,6,8	General
	Information seeking.	1,2,3,4,5,8	Typical
	Proactive behaviors and self-advocacy.	1,5,6,8	Variant
	Restorative coping.	3,4,5,6	Variant
	Meaning focused coping.	1,2,3,4,5,6,7,8	General
	Spiritual and existential coping.	2,3,4,5,6,7	Typical
	Helping others.	1,2,4,5,8	Typical
	Finding personal meaning in relationships.	7	Rare
	Emotion focused coping.	1,2,3,4,5,6,8	General
	Avoidance and compartmentalization.	1,2,3,4,5,6,8	General

	Provocative/angry responses.	3	Rare
	Resignation.	1	Rare
	Self-care activities.	6	Rare
	Cognitive adaptation.	2,4,5,7,8	Typical
	Use of humor.	2,4,7	Variant
	Optimism.	4,5,7,8	Variant
	Realistic perspective taking.	7	Rare
	Utilizing pre-existing skills.	1,5,7	Variant
	Animal companionship.	4,8	Variant
	Other: Exercise.	3	Rare
Impact of cancer on psychosocial wellbeing.	Changes in beliefs, attitudes, and behaviors.	1,2,3,5,6,7,8	General
	Attitude of gratitude.	1,2,3,6,7	Typical
	Recognition of new life possibilities.	2,5,6,8	Variant
	Spiritual and existential development.	2,3,6,8	Variant
	Greater appreciation of life.	5,7,8	Variant
	Changes in personal philosophy and priorities.	2,5,6	Variant
	Greater sense of personal strength and worth.	5,8	Variant
	Relational impacts.	1,2,3,5,6,7,8	General
	Improved relational health.	1,2,3,5,7,8	Typical
	Unsupportive/unhelpful responses from family and friends.	1,2,5,6,8	Typical
	Negative emotional impact on family and friends.	1,3,5,7,8	Typical
	Setting healthier boundaries.	2,5,6,8	Variant
	Feeling isolated from others.	1,2	Variant
	Loss of significant relationships.	8	Rare
	Negative emotional reactions to diagnosis or treatment.	1,2,3,4,6,7,8	General
	Negative emotional reactions to diagnosis.	1,4,6,7,8	Typical
	Negative emotional reactions to/during treatment.	2,3,6,8	Variant
	Chronic mental and emotional impacts.	1,2,3,4,6,7	Typical
	Anxiety about health and mortality.	1,2,3,4,6	Typical
	Fear of recurrence.	1,3,6,7	Variant
	Other: Vicarious trauma from exposure to other's cancer experiences and deaths.	1	Rare

	Other: Lack of awareness of cancer prior to diagnosis.	1	Rare
Other	Vicarious prior experience with cancer.	4,5,7,8	Variant
	Concurrent life events.	2,5,6	Variant
	Health behavior changes in family members.	8	Rare
	Reactions to study.	1	Rare

Domains and Categories

Experience with healthcare professionals and settings. Within the first domain, cancer survivors discussed the impact of their experiences with healthcare professionals and settings as significant factors in their cancer journey. These experiences were broken down into two categories: a) positive care experiences and b) negative care experiences. Two rare categories that emerged within this domain–e.g. mentioned by only one participant– are also described.

Positive care experiences. All eight of the participants in this study shared a story in which they felt they had experienced a positive interaction with a healthcare professional. While the definition of "health professional" for this category is fairly encompassing, the subcategories reveal the types of interactions that cancer survivors found personally meaningful within the healthcare context. The following subcategories further describe the positive experiences highlighted by cancer survivors.

Satisfaction with healthcare/treatment. Seven of the eight participants shared feeling that they received positive healthcare and treatment. A recurring theme among participants in this subcategory included a wide range of services offered during their time in cancer treatment. One participant shared that his providers made sure to offer him a wide range of services including: "…Anything, in terms of accommodating a change in

treatment time, or any sort of I guess holistic things that they could do, such as changes in diet, that sort of thing. So they were marvelous in that." Several other participants highlighted their appreciation for services and professionals, including nutritional consultation, massage therapy, psychiatric services, and genetic counseling. Another notable theme in this category was respectful communication between health providers and the participant. Several participants described how important it was to navigate their desires for treatment options with their providers. A participant with a positive experience stated: "I felt like they went through the whole process with me step by step, and knew me and understood me …they respected me throughout the whole process." One participant who chose to be DNR (*do not resuscitate*) shared her experience of having her treatment wishes respected: "You know, but they were really kind. I didn't know what they would do or how they would handle it, but I think they did really well. They probably thought I was a nut, but that is okay too!"

Receipt of positive psychosocial support. Relatedly, seven participants highlighted situations in which their non-biomedical needs were recognized and attended. Several participants highlighted how meaningful it was when providers asked if they needed to talk about their feelings related to having cancer and cancer treatments. One participant described her appreciation for nurses repeatedly asking: "Do you have any concerns? Is there anything you need to talk about? Is anything bothering you?" Another shared: "All the doctors, like I said, were amazing. They were so compassionate…I was all freaking out because I had never had an MRI before. And you know [they] just talked me through

everything." One participant, who received several rounds of painful radiation to his rectum, shared about his assigned radiology nurse:

> She reminded me of somebody who was like your wacky aunt who is always trying to help you out. She just made the experience. She always had a smile and was really cordial. So it made my experience not as severe as it could have been, for sure.

Another participant described her experiences with a hospital-assigned mental health counselor that worked with her during her time in treatment:

> She asked if she could do anything for me. She kept calling me to tell me that they had resources if I needed them. I liked it because it was someone that I could talk to. Because I really didn't have anyone to talk to about it, during that time. I mean… she was like a good support system for me, because at least I got to verbalize some of my feelings about it all at the time when I was going through it.

Appreciation for informational support from healthcare professionals. Six participants shared appreciation for strong informational support from healthcare providers. Participants described feeling comforted and empowered by careful discussion of their treatment options, side effects, and possible resources. One participant described feeling gratitude when she was provided a thorough orientation before the start of her treatment regime:

> [The radiation nurse] gave me her card, and told me that if I had any concerns that I could call her. After that, I met the radiation technologist, and they showed me the machines. They did all of that before anything was even started. It was a two-hour session.

Several participants shared feeling gratitude when providers outlined what they could expect in terms timelines for treatment and possible side effects. One participant shared, "Well, the surgeon of course was extremely helpful because she took the time to make sure that I understood everything that was going on and what was going to happen through every stage of it." Another shared feeling satisfied that her doctors trusted her with information about her prognosis and treatment: "I'm not sure how to put this… This may sound funny… they weren't trying to baby me. They were being up front and truthful with the information."

Appreciation for healthcare setting/system. One participant praised the organization of her healthcare system, and connected this to having a positive experience. She stated that health providers were constantly connecting her to one another within their system, and that they "offered everything from soup to nuts." The participant noted that they would gladly go back to the same hospital if they needed cancer treatment in the future.

Negative care experiences. Five participants shared having negative care experiences. Interestingly, participants' descriptions of negative experiences followed a converse mirror structure to components listed in the subcategories for positive care experiences. The four subcategories are described below.

Dissatisfaction with healthcare/treatment. Five participants shared having negative experiences in their healthcare and treatment. A major theme in this subcategory related to experiences of feeling unsupported or dismissed by their medical providers. One participant with a history as a researcher described having to go to several providers

before they would diagnose him with Cholangiocarcinoma, a particularly rare and deadly form of bile duct cancer, despite his presentation of sources and evidence to back up the likelihood of the diagnosis. Another participant, with a history as a nurse, shared a similar experience fighting with her doctors around her wishes for treatment:

> Well, like I said, my primary care sent me to get the mammogram in [state]. And then they did the diagnostic mammogram. I knew, being a nurse, I know what cancer feels like. So I knew it was cancer going into it. And they wanted to do the biopsy, and I fought with them and fought with them. That wasted a month about the biopsy/no biopsy. I made up my mind that I just wanted it out. And… uh… so then I had to find another doctor.

Another participant described feeling frustrated when medical providers performed procedures that they had not discussed with her, sharing "But it would have been nice to be told!", or when they gave her larger doses of painkillers than she felt she needed.

Lack of psychosocial support. Two participants indicated that they received a noticeable lack of psychosocial support from healthcare providers. When asked if they had received any information or support for mental health needs, one participant who highlighted feelings of anxiety and depression during his cancer experience, stated: "No. Nope. They talked about the physical stuff… That I might experience this pain, or this pulling. But… nothing about my mental state." Another participant highlighted feeling that her healthcare providers were often glib about her emotional response to losing her hair during chemo:

> And you know, not that anyone meant to be mean, but that was an area where I felt like people didn't give me enough… space to really express how traumatic

> that was for me. Because a lot of the doctors and the nurses were like, 'Your hair will grow back, don't worry, it will come back.'

Need for additional information and resources. One participant expressed a desire for more information from her doctors related to options for chemotherapy treatment. The participant described being told she would need to take a certain type of chemotherapy, only to find out later "that I probably wasn't given sufficient information about the kind of chemo, or the options that I might have for other chemos. The chemos that I used …were ones that were particularly aggressive…"

Discomfort or dissatisfaction with healthcare setting/system. Two participants noted a general discomfort with healthcare settings as impacting their cancer treatment experience. One of the participants shared feeling that his doctors in the hospital system were too busy, and noted that the system did not seem conducive to personalized care. The participant also described his stay in the hospital as stressful in terms of not being able to spend quality time with his family. "And I'd only get to see them [wife and daughter] for a few hours a day because my daughter couldn't hang out in the hospital …so I felt alone at the hospital a lot." The participant also stated: "Hospitals aren't a fun place." Another participant stated:

> I'm just not a doctor person. They are…. If I get really, really sick, I go to them. But otherwise they are just not someone that I want to see a whole lot. I'm not afraid of them, its not that I don't like them. I just, I don't know…

Other care experiences. Two participants noted other significant care experiences. One participant shared feeling put-off by his doctor's domineering

personality, despite being a qualified health professional. Another participant shared having notably positive experiences with her insurance providers, sharing that their insurance providers would check in once a month and helped her find a primary care provider post-cancer treatment.

Physical and functional wellbeing. Within the second domain, cancer survivors described various aspects of their physical and functional wellbeing as meaningful facets of their holistic wellbeing. In this domain, participant experiences were broken up into five categories: a) lasting negative impact on physical functioning, b) negative impact to physical and functional wellbeing during treatment, c) feelings of loss related to changes in abilities, d) increase in positive health behaviors, and e) satisfaction with current physical and functional wellbeing.

Lasting negative impact on physical functioning. Five participants highlighted long-term or permanent impacts on their physical and functional wellbeing as a result of undergoing cancer treatments. Lasting impacts ranged from permanent changes in bowel functioning, permanent loss of hair, loss of stamina, impairment in memory due to "chemo brain", and general experiences of chronic pain at various treatment sites.

Negative impact to physical and functional wellbeing during treatment. Three participants described negative impacts to physical and functional wellbeing more localized to their time in treatment. Major themes in this category included loss of physical functioning that contributed to changes in daily routines and activities. One participant described the exhaustion they felt during treatment, and noted being unable to operate a motor vehicle throughout her time in active treatment. Another participant

shared, “Umm… and then afterwards, the effects of the radiation were really pretty hard. I would just be…. I got progressively weaker as the session progressed. I got to the point where I was just dragging towards the end.”

Feelings of loss related to changes in abilities. Relatedly, three participants articulated feelings of grief or loss due to changes in abilities, either during treatment or long term. One participant that described losing his ability to exercise during treatment, which had previously been an important part of his wellness routine. He stated, “So not having that, umm… it was a shock to the system and a shock to the mind. I didn’t have that to fall back on.” Another participant described the impact of her treatment side effects: “But it was like… I felt incapable of doing anything. I didn’t like that feeling either.” The third participant described negative emotional responses to the long-term effects of his cancer treatment, which included permanent changes to his bowel function:

> Yep. Absolutely. You don’t realize how all encompassing that can be to your life. I mean, you think about going out to dinner with friends. You can’t do that anymore; you might have an incident after you eat. Intimacy with your partner. I mean you know you have to be careful of that. It is so all encompassing.

Increase in positive health behaviors. Five participants described an increase in their positive health behaviors as a result of their cancer experiences. Themes in this category included increased attention to regular medical check-ups, increase in exercise habits, and more thoughtful eating habits. Participants similar shared feeling that cancer had provided them with a kind of “wake-up call” or a “slap-in-the-face” about their health habits. One participant shared, “…it definitely made me aware of my limitations

and that I am not an 18 year old who can go out every night and drink a lot of soda pops. I have to take care of my body."

Satisfaction with current physical and functional wellbeing. Three participants noted that they felt satisfied with their current physical and functional wellbeing. Thematic in this category, participants expressed general gratitude that they were able to rebound from the physical side effects from cancer and its treatments, and felt general gratitude or pride in their improved health.

External supports and resources. The third domain touched upon the many external supports and instrumental resources that cancer survivors noted as significant in their experience with cancer. This domain also includes various external obstacles mentioned by participants, for which additional resources may have been useful. This domain was broken down into four categories: a) social supports, b) instrumental supports, c) informational supports, and d) obstacles and unmet needs. One rare category that emerged within this domain is also described.

Social support. All eight participants noted experiences with social support. Participants described social support as a significant factor in their cancer journey, and described social support from multiple sources. Subcategories were used to define the various sources of social support as described by cancer survivors in this study.

Social support from family and friends. Seven participants highlighted experiences of social support from family and friends. This subcategory included descriptions of positive feelings related to perceptions of support and emotional availability from close loved ones. Several participants shared about support from their

family members. One participant shared: “It was good for me to share with people about my side effects of the chemo… So I could talk to my parents about that, I had some kind of vocal outlet to tell somebody.” Another participant highlighted how important it was that her family supported her treatment decisions. Another participant highlighted support from her friends at work:

> Yeah. Again, like I said, I work with a lot of nurses. Nurses aids, being at the nursing home, I was very comfortable talking with them about it…. It was a cathartic type of thing to be able to talk to them about it. It kind of relieved some of my anxiety, along with that.

Social support from spiritual community. Two participants noted the importance of social support from their spiritual communities. One participant shared, “My church makes it really clear that they are there for us, that they pray for us, and they keep an eye on us.”

Social Support from online cancer support groups. One participant described the importance of an online support group for his cancer type. The participant noted that support group members would share information and encouragement with one another, and would occasionally meet up with one another when possible.

Connecting with other cancer survivors. Two participants described experiences receiving social support from other cancer survivors, both in treatment and beyond. One participant noted, “I’ve met a lot of people that have shared the cancer experience, and they are willing to reach out and respond back.”

Instrumental supports. All eight participants described experiences receiving instrumental resources and supports, which include any type of tangible aid, goods or

services (House, 1981). In this category, cancer survivor's described various instrumental supports they received, as well as sources of instrumental supports.

Instrumental support from family and friends. Six participants described experiences receiving instrumental support from family and friends. Themes in this subcategory-included help with home tasks and help getting too and from medical appointments. One participant shared about her mother, "She drove me to my chemos and sat with me and brought me home. She did a lot of things for my kids. I have three children." Notably, some participants highlighted friends and family members taking over new roles, or taking care of tasks previously done by the participant. One participant described her husband taking on tasks that had done before her cancer experience:

> My husband had to cook dinner all of the time, and I would tell him what to do. Or he would have to do the food shopping. He didn't mind cooking, he didn't mind cleaning… he didn't mind learning how to do laundry. I mean he knew how to do it, but he was doing it all of the time. But…. umm… the biggest thing for him was the food shopping.

Financial assistance from outside resources. Two participants described receiving financial assistance from outside resources, such as financial aid from the hospital or community charities, to cover medical or home bills. One participant described receiving help from her hospital through a Christmas present-buying program:

> So that was really helpful during treatment because it allowed me to still kind of have the normalcy of having gas in my car, being able to get lunch when I was out… having Christmas for my kids and not having to worry about that expense. And then that rolled over to my family not having to feel the cancer through the loss of some of this normal stuff… like not having Christmas gifts this year.

Financial stability. Four participants noted that they were able to maintain financial stability during their time in treatment. Notably, all of the participants expressed gratitude for their financial resources, and highlighted the tremendous expense of oncological care. One participant highlighted the importance of personal savings: "Financially, you know, I was lucky. I have a real job. It whacked us… It took a lot of money you know. If I hadn't had savings it would be hard." Two others highlighted the importance of health insurance, with one participant stating:

> I was dumbstruck when I saw the cost of the treatment. It was umm… $3,500 per treatment. And I had 44 of them. So [laughter], the math is quite a doozy. If I didn't have insurance I really would have been up a creek.

Choice of treatment facility/options. Two participants noted how important it was to have options when choosing a treatment facility. One participant noted that their insurance company allowed them to go to a higher-tier oncological facility:

> I never knew that even with my normal type of insurance that I could have gone to Mayo, or could Sloan Kettering… I didn't know. I felt that those were specialized places, only certain people get to go there… when I talk to other people they are same way, they say 'I don't think I can go there.' And yeah you can. If you have blue cross blue shield, call them up and say that you want to go there…. I had a pack of money in the bank, and thought 'if this keeps me alive, I will spend it all.' Not knowing that my insurance would pick it up.

Another participant noted the importance of treatment options when choosing which facility to go to, and noted that she was willing to drive farther away to go to a facility that provided more holistic options for treatment.

Transportation assistance from outside resources. One participant shared receiving help from a charity that helped them cover flights to get to the hospital:

> I'm not getting treatment at home, I have to travel a ways. I've had to drive that a couple of times, which can be a twelve hour drive depending on when you hit traffic. That can be a hefty drive, especially when you have a job. A group called Angel Flights has really helped me out a lot. Corporate Air network has helped me out a lot too. These places won't let us take our child, they did on our first flight but not since then… but they offer flights so that I can get to the hospital relatively easily if I need to. These are guys with just private planes who will pick you up on their dime and then take you down there.

Cosmetic resources. One participant shared how helpful it was to receive a custom-made wig after she lost most of her hair due to repeated chemotherapy treatments.

> And they actually make wigs specific to a patient, and donate those to you. So I did get a wig that was specific to me that I liked a lot. And I was very happy with it, it looked so much like my hair before that I felt that it was such a gift. I could go out and feel normal and not look any different than from before when I lost my hair.

Instrumental support from workplace. One participant shared the importance of their workplace providing support via flexibility with work scheduling:

> My coworkers, again my fellow CNAs and my director of nursing, were all really supportive. My director of nursing made sure that my schedule was changed to take whatever I needed to get to my doctors appointments. Even beyond the time that I was actually in the hospital and having surgery…. As I was going through radiation… to make sure that my work schedule didn't interfere with the radiation schedule. So all of those resources were really important for me. It made the whole process and situation so much easier to deal with.

Informational supports. Four participants described receiving informational supports. Themes in this category included the importance of receiving information related to cancer type, treatment options, and expected side effects during and after treatment. Participants described receiving informational support from several sources, detailed below.

Informational support from cancers support group web pages. Two participants shared receiving helpful information from online cancer support groups. One participant shared receiving information about his eventual doctor from an online cancer support group. Another shared: "There are forums, which I didn't actually get into but I read. So I was a lurker. But I read about people going through the same things and sharing their experiences online. So I read those regularly." The participant later highlighted that reading about the experiences of others also helped normalize their experiences.

From cancer foundation resources. Relatedly, two participants highlighted the utility of gaining information from various cancer foundation resources, most commonly informational materials found online. One participant shared:

> Mayo Clinic in particular had a very detailed yet easy to understand website devoted to what I was going through. I was able to get very deeply into the disease, the treatment…. so I guess what I am saying is that the technology and the internet today really empower people like me, or anybody else with cancer to have… light-years beyond what we would have been twenty years ago.

From family and friends. Two participants described receiving informational support from family and friends. Notably, sources of support in this subcategory were both medical professionals. One participant shared she, her daughters, and her sisters

were all nurses, and shared that she felt "covered" when it came to getting help understanding her medical needs and treatment options. Another participant described how their wife helped them navigate their medications:

> …she has a [doctorate] in pharmacy, she already had a background too. So she didn't know everything, but she knew a lot more about this than I did. She did the research… she was able to do it on her own…. And she was able to understand the compound drugs and the interactions of the body, how it would be.

Obstacles and unmet needs. Seven of the participants highlighted various external obstacles they faced in dealing with cancer, or suggested resources that might better assist cancer survivors in navigating the cancer experience. This category was broken down into six subcategories, as described below.

Financial burden associated with cancer. Six of the participants mentioned the financial burden associated having cancer and undergoing treatment. Financial burden from cancer includes impacts to cancer survivors during and after treatment. Several participants described their struggles to pay hospital bills from their time in treatment. One cancer survivor described the experience of financial difficulties resultant from lasting functional disabilities acquired after treatment for cancer. The participant noted that they can no longer work a regular job.

Access to care. Four participants noted the importance of distance as a barrier to care access. Themes in this subcategory include challenges faced by individuals in rural areas to get access to basic oncological services, or to have access to more specialized or holistic oncological services. One participant stated, "So yeah, I think distance to treatment matters." Another participant noted that she would have liked to attend a cancer

support group, but was limited by her distance to the hospital in which the support group was held:

> And [the main hospital] where they seemed to hold most of that stuff… And I wonder why there isn't anything out at the breast center, or maybe farther out where I had my biopsy at the smaller hospital. And no one had real answers for that. There just wasn't anything, you know.

Scarcity of resources and information. Two participants noted feeling that there was a general lack of resources or information for individuals with their cancer type. Themes in this subcategory include lack of information related to symptoms, treatment options, or wellness resources for less common cancer types. One participant described the need for individuals with their cancer type to find information for one another:

> Yeah, I don't know about the more common ones where there is a lot of stuff out there…. If you have breast cancer there is a lot of stuff, if you have prostate cancer there is a lot of stuff… So I don't know about the more common ones. But these more obscure ones, yeah we have to dig for each other.

Need for supportive follow-up care. One participant described feeling a need for more supportive and specific follow up care:

> When I first got this, the first day that I was down there… they had a social lady that we spoke to for a few minutes who gave me a card with a number, but there was no follow up to it. I don't want to say that she or they were indifferent, but the stuff they were talking about was very generic, it wasn't specific to me.

Desire for increased societal awareness of cancer and its effects. One participant stated frustration that societal structures are not better prepared to understand and assist cancer survivors as they attempt to reintegrate their lives post-treatment. The participant

shared stigma around sharing his post-cancer physical and functional limitations. The participant also went on to say: "I'm pursuing disability with social security… I don't know how far it's going to go, I do not think that they recognize my issue or understand what I am dealing with."

Limited or no social support. One participant stated that she had almost no social support during her time in treatment (e.g. "There was no support at all."), but noted that she was able to move closer to family to receive social support once she was done with treatment.

Other external supports: experiential activities through cancer organizations. One participant described feeling positively about various experiential activities she was able to engage with after her time in treatment. The participant noted that several cancer organizations provide experiential trips such as hiking and mountain climbing to help cancer survivors find new meaning after their time in treatment. This was notably a rare category.

Psychosocial coping strategies. Within the fourth domain, cancer survivors described the various coping strategies they utilized to navigate treatment and survivorship. This domain was broken into six categories: a) problem focused coping, b) meaning focused coping, c) emotion focused coping, d) cognitive adaptation, e) utilizing pre-existing skills, and f) animal companionship. One rare category that emerged within the domain is also described.

Problem focused coping strategies. Seven participants described utilizing problem focused strategies. The coping strategies described in this category were

generally utilized with the intention of solving some kind of problem in order to help the participant feel better about their situation.

Information seeking. Six participants described the importance of seeking information in coping with cancer. Themes in this subcategory include participant efforts to obtain information about various options related to treatment and general problems resultant of a cancer diagnosis. A couple of participants highlighted the need for information as pre-eminent to their need for emotional support during the diagnosis and treatment stage, with one participant sharing:

> It is more of a thing where I need facts. I need to know what to expect, what is going to go on. Pending those answers, information about what is going to happen, the need for more emotional support may come.

Another participant noted that, while not all cancer survivors will feel ready to emotionally handle a lot of information during early stages of treatment, she felt she needed as much information as possible:

> Right, some people wouldn't be able to hear it. I understand that. Everybody functions and copes in a different way. And so, you know, that was my personal experience, as someone who… Some might say I'm controlling… But I just want to know as much as I can know that is going on so that I can do as much as I can, you know, during the process too. If that makes sense. So some people are like that.

Another participant who described information seeking as an important coping method also touched upon some of the negative impacts of this coping style in their life, stating:

> Though it still puts you in a weird spot because you wonder which of the stats to believe. Do I keep reading stats to better educate yourself? It can also put you in a tailspin of research that you probably shouldn't go down. But it is like a train wreck.

Proactive behaviors and self-advocacy. Four participants described the importance of self-advocacy and proactive behaviors in coping with cancer. Themes in this subcategory included active efforts to seek and stick with treatment regimes, self-advocacy in navigating treatment decisions, and seeking out external resources. One participant described proactive behaviors as an important coping tool in dealing with the shock of finding out that she had cancer:

> My response to that shock was, 'Well I have to wait til my family gets home to tell everyone.' So in the meantime I got online and started looking for resources… I have suffered from depression on and off in my life. And so, you know, I feel like my way of coping with that has been to try and reach out and find opportunities and other people to surround myself with that get it. And so that was my first natural reaction when I found out that I had cancer… I can't imagine not having done that, because if I had just sat here to myself and had not reached out… If I had done that, I think my depression would have overwhelmed me. It's such an intense thing.

Restorative coping. Four participants described facets of restorative coping, which may be understood as a type of coping focused on returning to their life as it was before cancer, or adjusting to their new normal, as expediently as possible. Themes in this subcategory included a focus on getting through treatment, and a general outlook of personal determination to overcome obstacles. As one participant stated, "I wasn't going to let anything stop me from doing… from living my life. I was going to get through it and be fine and live out my life to a ripe old age." Another shared similar sentiments:

> All I know is that I wanted the cancer out of me. One way or the other. I had the urgency to do that. It was like the highest urgency in my mind. And then I knew that I was just going to get this done and get one with my life. And have a life. And I am doing that now

Another participant described a restorative coping focus after treatment had ended:

> And once it was over and done with, it was just like, okay. Let's get on with my life, you know. Let's get to physical therapy. Let's get radiation done. Let's get moving back so that I can drive and get back to work. And I can function like a normal human being again…

Meaning focused coping strategies. Eight participants described the utilization of meaning focused coping strategies. In this category, participants described various methods of making meaning of their experiences in order to better cope (e.g. *How can I make this experience mean something?*).

Spiritual and existential coping. Six of the participants described utilizing spiritual or existential beliefs to cope with and make sense of their experiences with cancer. One participant described the importance of connecting with their higher power, stating: "But as long as I continue to place my faith, spiritually speaking, in something beyond myself, in someone beyond myself… I'm really doing just fine." Several others highlighted the importance of believing in a larger design for their lives, with one participant stating: "I don't attend religious services…. But I do meditate. I do believe in God, I believe there is a reason for everything. There is a plan mapped out." Another participant specifically highlighted their peace with the concept of death as an important coping mechanism:

> I would say I've come to peace. You know… after having done hospice and attending many deaths, you know, not everybody has that perspective and that is something I have dealt with for a number of years… And you know, death is not a horrible thing to me… I mean a lot of people don't want to talk about death, and I don't get that.

Helping others. Five participants highlighted helping others as a meaningful coping tool. Themes in this subcategory included provider information to other cancer survivors or family members, or providing encouragement and/or gifts to others going through treatment. One participant shared that it was important for her to give back to others in treatment: "I baked cupcakes for everybody in the chemo room. I was making bracelets and handing them out to all the other ladies." Another participant highlighted the importance of contacting other family members that might be at risk for breast cancer:

> I contacted my sister, because the doctor had said that because my mother had had it and died from it, there was this percentage increase about it happening in other family members. So my first thought was to contact my sister to make sure that she was getting her mammograms annually. I contacted my daughter to make sure that she was aware of that. You know, so it was maybe a protective thing. I found it necessary to contact family members. Not so much to let them know that I had it, to be sure that they were doing what was necessary.

Finding personal meaning in relationships. One participant described the importance of finding personal meaning through the strength of her relationships with her family members throughout her cancer experience.

Emotion focused coping. Seven participants described utilizing emotion focused coping strategies. Emotion focused coping may be understood as efforts to manage emotional responses to better navigate a situation, and may include the management of internal emotional responses, or external emotional interactions.

Avoidance and compartmentalization. Seven of the participants highlighted the importance of avoidance and compartmentalization at some point during their cancer journey. Many participants highlighted the importance of avoidance and compartmentalization during early phases of treatment. One participant shared:

> Well, a lot of people, when I was diagnosed and didn't tell people… they were mad at me. And I had to be like, 'Well, its mine. Yes I love you. Yes you are part of my life. But it is my business.' I couldn't deal with it. I couldn't talk about it. I didn't want to sit here and cry all of the time. I just wanted to go from day to day until it was finally taken care of.

Another participant described feeling that they avoided processing their emotions during treatment because they were not ready or were unprepared to handle their feelings about their cancer experience:

> Because when I was going to chemo, I'm telling you… I did a lot of stuffing I guess. I came in with my wig on, and dressed up, and lipstick…So I was just kind of skipping through all of the difficult stuff and not really processing.

One participant connected her need to compartmentalize with her desires to emotionally attend to her family members:

> My parents. It's going on four years now… so they were in their early eighties. I didn't want to say anything to them until I knew exactly what was going on because I knew it would affect them.

Some participants also described feeling the need to compartmentalize their feelings after treatment had ended. A few participants highlighted feeling unsure that others would know how to support them if they shared their experiences, or worried that they would

receive pity rather than empathy. One participant that noted feeling comfortable sharing her feelings with the interviewer reflected:

> There aren't a whole lot of people that I connect with to that level that I guess I feel comfortable talking with… And I'll say, some people… like yourself… I don't know what, I couldn't explain it for the life of me. There are just some people, whether I know them or not, that I feel comfortable talking to. Others, there is just something about them that puts me off. I have no idea what that is. It is just my feelings. It is how they approach me. If somebody approaches me with this… sympathy, pity… I'm not going to talk to you because that is not what I'm looking for.

Provocative/angry responses. One participant shared the experience of coping with the early stages of treatment by reacting with aggression towards his medical care providers. The participant went on to connect this coping reaction as a way to feel more in control:

> But I also took my own… stand on it. By, umm, being somewhat of a jerk with the physicians, and viewing them almost as an adversary, I guess. Ummm… where I was questioning what they were asking, and what their medical qualifications were. By background, my father was a radiologist, and he always encouraged me to heavily question any medical treatment that you are getting… I was being an ass, to put it plainly… [I wish that I] had I just looked back and said, 'You know, I'm just trying to exert some control over the situation.' And unfortunately, the medical community was on the receiving end of it.

Resignation. One participant shared feeling the need to be emotionally resigned when he was not able to receive the support that he wanted from care providers:

> It was a world-class cancer center, and there were probably resources I could have sought out… but when I got the feeling that I was just another number in their group… when the support wasn't really headed where I wanted it to go… I just dropped it.

Self-care activities. One participant highlighted the use of self-care activities in managing her emotional responses to dealing with cancer and its effects:

> Even if it is only for an hour or two, I try to find me time. I love to read, I've always loved to read. I love to do jigsaw puzzles, so there is always a jigsaw puzzle on the dining room table. Just something to sit if I feel myself getting overwhelmed. Something to get me right back into my groove. Something for me.

Cognitive adaptation. Five participants described coping experiences congruent with cognitive adaptation, which may be understood as coping methods that attempt to shift one's cognitive perspective of a situation in order to feel better. More detailed descriptions of participants' uses of cognitive adaptation can be found below.

Use of humor. Three participants described the importance of finding humor in their experiences as a meaningful coping mechanism throughout the cancer experience. Within this subcategory, several participants highlighted the role of others in helping them shift their perspectives on their experiences. One participant described the emotional and physical challenges of receiving almost-daily radiation treatment for his rectal cancer:

> And by that point I had no shame, I was walking around with nothing on but a gown and a smile, and they just lift it up and they zapped my butthole. And it was like, there is nothing at that time that I could hide. [laughter] And [the radiology staff] did a lot to help me feel comfortable, and to maybe even laugh about it. They really had the right attitude. It helped significantly with that time.

Another participant shared a story of finding humor with her co-workers after she finished treatment for breast cancer:

> The nurses at work were just fantastic…Yeah. Absolutely. I mean they helped me kind of laugh at the situation, so to speak. They had a booby party; they had cupcakes made [laughter]. It was kind of a fun way to end the situation.

Another participant, when asked about her many comical interpretations of her cancer experience during the interview, reflected upon her self-described need to find the lighter side, stating: "But yeah, I mean I figure if you can laugh a few minutes that adds a year or two to your life [laughter]. I mean that's not realistically true, its just… its just a nice thought…"

Optimism. Four participants described utilizing optimism. In this subcategory, participants described the importance of being hopeful, and paying more attention to the positives. One participant shared:

> Anyhow, after it was all said and done… [the doctor] said that I had a 15% chance of it reoccurring. And I said, 'Well I've got an 85% chance that it wont.' So I'll take those odds at my age.

Realistic perspective taking. One participant noted the importance of keeping a realistic perspective during her cancer experience. The participant stated that it is important to avoid negativity, but remarked: "But you also have to be realistic. I mean, death and taxes. That's it. No body gets off this planet without dying. So far."

Utilizing pre-existing skills. Three participants highlighted the importance of utilizing pre-existing skills to navigate their cancer experience. Notably, of the participants that shared experiences within this category, one identified as an academic researcher, and two identified as nurses. As one participant shared that her experiences as a nurse helped her navigate her treatment and feel more comfortable with healthcare

providers, and stated: “I mean, I know the ins and outs of a lot of what goes on in the hospital.”

Animal companionship. Two participants described the importance of relationships with animals as meaningful coping mechanisms. One participant described how important it was to have her dog at her side when she went to chemo, or when she was at home recovering from treatment. Another shared:

> Like I said we lived in a rural area and had a little farm. I had horses and cows and dogs and cats… And some times my horses were a better therapy… Yeah. I could go out to the pasture and the horse would come up and lay her head on my shoulder, and we would just talk. So like I said they were probably a better therapy for me.

Other coping strategies: Exercise. One participant described utilizing exercise as a coping tool, calling it a “security blanket”. The participant also noted that it was personally challenging to temporarily lose the ability to exercise during his time in treatment, and was thankful to regain his ability to exercise post-treatment.

Impact of cancer on psychosocial wellbeing. Within the fifth domain, cancer survivors described various salient psychosocial impacts on their wellbeing due to their experience with cancer. This domain was broken down into four categories: a) changes in beliefs, attitudes, and behaviors, b) relational impacts, c) negative emotional reactions to diagnosis or treatment, and d) chronic mental and emotional impacts. Two rare categories that fell within this domain are also described.

Changes in beliefs, attitudes, and behaviors. Seven participants described experiences with cancer that resulted in changes to their beliefs, attitudes, or behaviors. This category was broken down into several subcategories, as described below.

Attitude of gratitude. Five participants described feeling a general sense of gratitude in relation to making it through their cancer diagnosis. One participant noted how happy they were to make it to another birthday. Another participant remarked:

> So my bottom-line is this: I am good. I am, I almost feel guilty that I am in good of shape as I am. I am very fortunate, even with my difficulties. That is my overall outlook on everything that has happened to me.

Participants also described general feelings of gratitude for supports, namely family and friends, which aided them in making in through their time in treatment. One participant shared, "Looking back on it, again, I am touched by the level of concern and love that people in my life have for me."

Recognition of new life possibilities. Four participants described recognizing new life possibilities as an impact of their cancer experience. Themes in this subcategory included a new awareness of opportunities, such as going into early retirement or moving closer to family, that were more in line with participants desires for their lives. One participant described the decision to quit his job, shared:

> I mean, its like… Look, I just faced a very traumatic experience in my life. Why do I want to go back to feeling how I did in my job over again? […] The timing was already there, but I think that [having cancer] put the cherry on top of the ice cream for it. It was like, life is too short.

Another participant described having cancer as a type of "wake-up" call, and decided to leave a toxic romantic relationship that she had been engaged in for several years. The participant went on to say: "I felt that I had a second chance. Make the most of it. I didn't want to waste any more of my life."

Spiritual and existential development. Four participants described development to their spiritual or existential beliefs as a result of having cancer. A couple of participants described feeling that they had a deeper connection to their god as a result of having cancer. Another person shared feeling they had a healthier spiritual perspective since having cancer, but noted that their process involved coming to peace with feelings of anger that God had allowed them to get cancer.

Greater appreciation of life. Three participants described having a greater or heightened appreciation of life. In this subcategory, participants described feeling more grateful to be alive each day, with one participant stating: "When I go to sleep at night the last thing I think of is *I'm so thankful*." Another shared:

> So, I'm trying to be more aware of that, more thankful. That, you know, I have been given some extra time that I could potentially not have had. So I see how I am more fortunate than I was really thinking of myself during [time in treatment].

Changes in personal philosophy and priorities. Three participants shared experiencing changes to personal philosophies or priorities as a result of having cancer. In this subcategory, participants described feeling that their philosophy or approach to life had shifted in a noticeable way. One participant shared:

> I don't take myself so seriously anymore… No matter what it is, I know that I can get through it. You know? You know, I mean how bad is it? I mean really, it is going to work out how it is supposed to. Sometimes you have to stand back and just let that happen, maybe you try not to interfere with it. And worrying about something doesn't change it. It just makes you sick.

Two participants noted changes to their political philosophies as a result of dealing with the financial burden of cancer. One participant described this change:

> Umm, I'm a pretty free market guy when it comes to economics. Ummm, but what I went through has convinced me that we need to have socialized medicine in this country. And my father would roll over in his grave if I said that. But the fact of the matter is, and you hit it right, unless you have insurance, you are not going to be able to get the level of treatment that I got. And, for these millions and millions of folks in this country that don't have insurance… I mean their options are limited. And so I have become convinced that we need an overhaul of the healthcare system –far, far more radical than the Obamacare package– which would allow anybody to walk in any hospital and get the same triple A treatment that someone with insurance would have, or that a congressmen or a senator would have. I've become almost a communist in that respect.

Greater sense of personal strength and worth. One participant noted that they had a greater sense of their personal strength and worth as a result of having cancer. The participant described feeling that they deserved a better life than the one they had lived before, and were no longer hesitant to live their best life.

Relational impacts. Seven of the participants shared experiences describing impacts to their personal relationships as a result of having cancer. This category was broken upon into several subcategories, as described below.

Improved relational health. Six of the participants described noticing improvements to one or several important relationships as a result of going through their cancer experience. Themes in this subcategory include an increased awareness of the

value of their personal relationships, feeling closer to loved ones as a result of going through the trauma associated with cancer, and increased commitment between participants and loved ones due to a heightened awareness of mortality. One participant shared a new dedication to communicating authentically with their partner after having cancer:

> I would say that we are probably more normal now than we were prior to this diagnosis…We are not as just living a very lovey-dovey kind of with blinders on like we were. I think, in some part of me I've always held back if something was off with people… So I've noticed over the past couple of years, especially, that we have been more… normal… And we had a discussion about it one time where my wife said, 'You don't seem like you are happy with me.' And I told her that it wasn't that, it was just like I am over some of this trying to hide how I actually feel. I'm not going to suppress things so much. I'm going to be a bit more vocal about things. And that can be considered negative, but it can also be considered a positive in that you aren't hiding anything.

Another described feeling that having cancer had made him closer to his daughter, sharing: "I would say that I am closer with my daughter. I don't know if I would be as close to her otherwise. But I feel that I am probably closer to her…" Another described growing closer to her mother after her mother helped her care for her family during treatment, stating: "And that was actually really a positive because we weren't always particularly close. But I think that my mom kind of… it was a wakeup call for her too that, 'Wow my daughter might die before I do.'"

Unsupportive/unhelpful responses from family and friends. Five participants shared that they felt they had received unsupportive or unhelpful responses from family and friends. Some of the participants noted feeling underwhelmed or disappointed with the amount of outreach that they received. One participant shared about his experiences

when his perceived friend group avoided him after he received his diagnosis: "These people that I thought were my friends, but they weren't. But that disappointed me… I kind of saw their true colors really." Another shared frustration by family and friends that attempted to comfort them by comparing their cancer experiences to others':

> I didn't want to hear after that I said that it was DCIS stage one… I didn't want to hear, "Oh thank God you don't have stage 4 like my friend down the way…." You don't want to hear that. You just don't. This is your body, you are going through it, and they are not… And that's the only negative that I can say. People just didn't understand when I didn't want to talk about it, or when I got upset when they were trying to comfort me to let me think that someone else had it worse.

Another participant noted frustration when a family member was unsupportive of her choice for treatment:

> Well, [my sister] with me at all. With my approach to how I was going to do treatment. And I, like, I told her, 'I was supportive of you, whether I agreed with you or not, I kept my mouth shut.'… She really felt that if you did the chemo, it was 100% insurance that you would re-get it. I told her that she was wrong, but I didn't interfere in her decision and I asked her not to interfere with mine. I think you should be supportive, or don't call.

Negative emotional impact on family and friends. Five participants shared that their experience with cancer had a negative emotional impact on family and friends at some point during their cancer journey. Several participants highlighted how difficult their cancer diagnosis was on their loved ones, with one participant highlighting, "And it was pretty difficult and devastating for [them]. Because they were afraid that I was going to die too." One participant shared how challenging it was for him and his wife to navigate telling their daughter that he might die, sharing how unprepared they were to

find the best way to educate her about death. Other participants described how the negative impact on family and friends put stress on their relationships at some point, with one participant sharing:

> And I was thinking that I was presenting as well as I could, so my husband should be doing fine right? And I found out that that wasn't true. He actually had a nervous breakdown right around the time that I had finished my treatment… We were separated for about three months… We also stayed in contact and did a lot of different therapy and things to kind of get back to a good place, which we have.

Setting healthier boundaries. Four participants described learning to set healthier relational boundaries as a result of their experience with cancer. Themes in this subcategory among participants included needing to create space from unhelpful or toxic individuals, learning to avoid seeking support from unhelpful sources, and having more realistic expectations within interpersonal relationships. One participant shared that is was important to avoid talking to unsupportive family members during her time in treatment. Another shared learning that she could not change those around her:

> There are certain people that I deal with a lot, umm, family wise that can just… push my buttons. I've learned after this that it is not worth it. It's just not worth it. They are not going to change no matter what I want, so I have to deal with people differently.

Feeling isolated from others. Two participants noted feeling isolated from others during their experience with cancer. In this subcategory, participants shared feeling lonely or uncared for, or described feeling that no one would be able to connect with them. One participant highlighted that he tends to hide these feelings, stating: "It's an interior type of isolation. From the exterior you wouldn't know it."

Loss of significant relationships. One participant shared that she had lost a significant relationship as a result of having cancer. The participant described how her mother-in-law had encouraged her husband to leave her during her cancer treatment and remarked:

> I don't speak to her, our family does not, because I think at that stage when we were separated she had told them that he should just go ahead and leave because he didn't need to have to deal with if I were to get sick again or if I would have died…. Because that was such a hassle and… She was saying that it would be better to cut his losses now and move on. And I was just like, 'What? My Mother-in-law of all of these years.'

Negative emotional reactions to diagnosis or treatment. Seven participants shared having a significant negative emotional reaction to their diagnosis, or to/during their time in treatment. Themes in this category include feelings of hopelessness, shock, sadness, and anxiety. This category is broken up into two subcategories, as described below.

Negative emotional reactions to diagnosis. Five participants described experience a negative emotional reaction when they found out that they had cancer. One participant shared, "I went home, freaking out, knowing that this thing kills almost everyone who gets it." Another shared her anxiety waiting for her prognosis after finding out that she had cancer:

> [It was] more like a… 'Why me?' kind of thing. 'Why is this happening?' Because there is no breast cancer in my family. Maybe a second cousin had it, but there is no breast cancer in my family at all. 'What am I doing wrong that caused this?'… I thought about myself, I was worried about myself. But then thoughts like, 'Am I going to see my son graduate college? Am I going to see my son get

> married?' All of these thoughts running through my mind. 'Is this, like, a fatal?'... And maybe fatalistic thoughts. I mean because I didn't know, I had no idea.

One participant stated that they felt immediately depressed and fearful, while another described feeling "like someone had punched [me] in the gut."

Negative emotional reactions to/during treatment. Four participants described having negative emotional reactions to or during their time in treatment. One participant described feeling powerless, "like something had overtaken me that I couldn't address on my own." One participant remarked of her time in radiation:

> I would go in and be very emotional and weepy in these times. I think it was because I was nearing the end of the treatments. And even though that was an easier physical thing, it was kind of like you had held it in all through the chemos, and the tough stuff. So the easy stuff, that is when I started to kind of fall apart emotionally…. Letting go of some of that, you know… anger… There is some shock, you know. You go through the different grieving stages.

Several participants highlighted feeling emotionally and physically drained during treatment, sharing emotional experiences that ranged from fearful to frustrated and cranky.

Chronic mental and emotional impacts. Six participants described experiencing chronic mental and emotional impacts. This category is broken up into two subcategories, as described below:

Anxiety about health and mortality. Five participants described feeling a heightened sense of anxiety about their health/and or mortality as a result of their experience with cancer. Several participants describe feeling more nervous about their general health after having been diagnosed with a serious illness such as cancer. Another

shared feeling more anxious about medical appointments generally, stating, "I am always very fearful of what the doctor might say, almost to the point where I don't want to deal with it. Sometimes I feel like I want to just dig my head in the sand."

Fear of recurrence. Four participants shared specific fears of their cancer recurring. One participant shared, "I mean in the back of my head, do I think, 'Could it come back?'… Yeah. It scares the hell out of me, don't get me wrong." Another participant with a more aggressive cancer type stated: "Knowing that the recurrence rate is around 60% in most studies, I kind of just walk around everyday waiting for the shoe to drop."

Other impacts on psychosocial wellbeing. Two rare categories related to impact of cancer on psychosocial wellbeing emerged in this study. One cancer survivor described feeling vicarious trauma as a result of being exposed to other's cancer experiences and deaths with his same cancer type. The participant shared:

> But the shit part is that you have people that you know people who constantly die. We had one person [in my support group] die yesterday, one person die the week before, and a couple weeks ago we had three people die during the same week. Umm… you have one young girl in [location redacted] who had it metastasize to her brain. You know, here we are saying, 'Well gosh. Here is this 25-year-old girl and there isn't a damn thing we can do for her.' And we know her.... But it is different when this is someone that you've actually met and you touch their hand and they die on you, you know?

The same participant also shared experiences in a second rare category: feeling a lack of awareness of cancer prior to diagnosis. The participant described being shocked by the impact of cancer, and learning of the high rates of cancer occurrence in the United States.

Other. The last domain included facets of participants' experiences that seemed relevant to the study, but did not fit within the other domains.

Vicarious past experience with cancer. Four participants shared vicarious experiences with cancer before their own cancer diagnosis. Participants further highlighted ways in which these vicarious experiences impacted their own cancer experience. One participant described how her mother's experience with cancer impacted her:

> With the breast cancer, it took me back a little bit. Probably not so much because I had the cancer, but because my mother had breast cancer, which she died from. Yeah… it took a while for me to get over this 'Where is it going? What kind is it? How big is it?', you know… 'How long was that lump in there'…. You know?

The participant later identified feeling an increased sense of concern about her prognosis as a result of losing her mother to cancer. Three participants highlighted how their vicarious experiences impacted their own choices for cancer treatment. Another participant described how her sister's previous experience with cancer created an increased sense of anxiety in her family when the participant shared that she had cancer: "They were expecting the same situation. You know, cancer meant BAD… They were scared." The participant went on to share that her decision to seek out an oncological specialist for her treatment was impacted by her sister's unsuccessful experiences with a general surgeon.

Concurrent life events. Three participants described significant life events that happened concurrently, and consequently interacted with, their experience with cancer. One participant described losing his father and both of his wife's parents within four

years of his cancer diagnosis. The participant described the added emotional challenge of these losses, as well as existential questions that resultantly arose. The participant linked these experiences to other cancer impacts, such as his awareness of new life possibilities. Another participant described her experience finding out that she had cancer while in an abusive romantic relationship of over twenty-years. The participant noted that cancer helped her realize that she no longer needed to be in that relationship, and felt empowered to live a more meaningful and fulfilling life. She shared:

> I feel good. When I had the cancer I was living in [state] with a domestic partner. And he was very verbally abusive. And he beat me down constantly with his mouth. To the point that he was saying, 'I hope you have cancer, it will serve you right.' Umm, you know, now that I am away from all of that, and I have been for a couple years, I'm good.

Another participant described her pre-cancer diagnosis role as the main care-giver to both of her elderly parents. The participant described her parents as largely bedridden, and shared that she was "was always running to the supermarket for them", "going over there and doing their bills", or managing their "ten or twelve different medications". The participant described how significant it was for her to need to delegate these duties to other family members, as she was unable to continue as their caregiver while she was undergoing treatment for cancer.

Health behavior changes in family members. One participant shared that her daughter had established healthier eating habits as a result of the participant being diagnosed with cancer. The participant shared about her daughter:

> She cares about what is in the food, she doesn't want us to eat as much sugar. She wants us to eat less meat, you know, and do more activities… I think this all changed her because she was running along and eating fast food and drinking sodas before I got sick. Now she totally rejects that.

Reactions to study. One participant noted gratitude for the content of the study in relation to cancer survivors' psychosocial wellbeing, sharing, "Well, I'm glad that you and other people are starting to look into this."

Integrated Analysis

The integrated analysis was designed to answer the fourth research question: Are current models consistent with the identified salient psychosocial factors in the lived experiences of cancer survivors? To complete this analysis, the primary researcher reviewed the results from both study phases, and explored how the qualitative findings might help explain the quantitative results.

As previously outlined in this chapter, both of the wellbeing models explored in this study were shown to account for significant variance in the dependent variable (dv= depressive symptomology, as measured by the CES-D-10; Andersen et al., 1994). The QoL model (utilizing the FACT-G subscales; Cella et al., 1993) was shown to account for 66% of the variance in depression scores, whereas the wellness model (utilizing the FFWEL-A subscales; Myers & Sweeney, 2005b) was shown to account for 48% of the variance in depression scores. In a combined model, the subscales of both models were shown to account for 73% of the variance in depression scores. Notably, 57.1% of the sample in phase 1 and 37.5% of the sample in phase 2 (sampled from phase 1) were found to have significant depressive symptoms. As discussed in chapters 1 and 2,

depression is a significant psychosocial outcome of the cancer experience (e.g., Honda & Goodwin, 2004; Irwin, Henderson, Knight, & Pirl, 2014), these models do account for some significant psychosocial factors experienced by cancer survivors, based upon the quantitative results alone.

However, analysis of phase 2 results in conjunction with phase 1 results, and the wellbeing models employed therein, reveals a more complex analysis of QoL and wellness models in capturing the salient psychosocial needs of cancer survivors. In phase 2, CQR analysis of 8 semi-structured interviews resulted in the creation of seven domains, with one domain "cancer profile" being excluded from cross-analysis, and 23 categories labeled general, typical, or variant, and 8 rare categories (see Table 9). Notably, variant or rare categories may still reveal meaningful experiences of wellbeing in cancer survivorship. However, wellbeing models must strike a balance between appropriate levels of complexity and overwhelming intricacy; therefore, researchers utilizing holistic models of wellbeing should prioritize factors (Jamner & Stokols, 2010). For the purposes of this analysis, only categories with general or typical labels will be analyzed.

The ten general categories included: (a) positive care experiences, (b) social support, (c) instrumental support, (d) obstacles and unmet needs, (e) problem focused coping, (f) meaning focused coping, (g), emotion focused coping, (h) changes in beliefs, attitudes, and behaviors, (i) relational impacts, and (j) negative emotional reactions to diagnosis or treatment. The five typical categories include: (k) negative care experiences,

(l) lasting impact on physical functioning, (m) increase in positive health behaviors, (n) cognitive adaptation, and (o) chronic mental and emotional impacts.

Notable categories within the first domain, experiences with healthcare providers, included: (a) positive care experiences (general) and (k) negative care experiences (typical), do not appear to have connected content on either of the models explored in the current study. However, previous versions of the FACT-G (Cella et al., 1993) did include an item related to *relationship with doctor*. Notable subcategories within the domain include: "satisfaction with healthcare/treatment" (general; category a), "receipt of positive psychosocial support (general; category a), "appreciation for informational support from healthcare professionals" (typical; category a), and "dissatisfaction with healthcare/treatment" (typical; category k).

Within the second domain, physical and functional wellbeing, two typical categories emerged: (l) lasting impact on physical functioning and (m) increase in positive health behaviors. The FACT-G model includes seven questions related to physical wellbeing (e.g. *I have a lack of energy*; *I am bothered by side effects of treatments*), all of which may connect to category (l) lasting impact on physical functioning. The FFWEL-A provides some content related to category (m) increase in positive health behaviors (e.g. *I eat a healthy diet*; *I get some form of exercise for 20 minutes at least three times a week*). However, both of these categories relate to changes in physical and functional wellbeing after time in treatment, and neither of the models explored were designed to assess post-treatment wellbeing in cancer survivors.

The third domain, external supports and resources, generated three general categories: (b) social support, (c) instrumental supports, and (d) obstacles and unmet needs.

The following general category, (b) social support, has corresponding content with the FACT-G (e.g. I *get support from family and friends*) and the FFWEL-A (e.g. *I have at least one person in whom I can confide my thoughts and feelings*). Notably, the only general (or typical) subcategory found within the category of social support was "social support from family and friends". General category (c) instrumental supports, relates to functional and instrumental resources utilized by cancer survivors, and had one typical subcategory: "instrumental support from family and friends". Additionally, general category (d) obstacles and unmet needs relates to the many situational challenges experienced by cancer survivors, and had one typical subcategory: "financial burden associated with cancer". Content across both categories included themes related to coping with changes in finances in relation to functional changes in the home environment (e.g. loss of income, limited ability to continue regular household tasks, travel needs from home to treatment, etc.) as well as increased need for cancer-related services (access to care, access to health information, etc.). At least two items on the FACT-G relate to content within these categories (*Because of my physical condition, I have trouble meeting the needs of my family*; and *I am able to work*). Three questions in the FFWEL-A include content related to instrumental support (*I have friends and/or relatives who would provide help for me if I were in need*; *I have friends who would do most anything for me if I were in need*; and *When I need information, I have friends whom I can ask for* help).

Neither model includes questions specifically related to financial wellbeing, leaving this category identified as salient to sample participants unaddressed. Relevance of financial and functional impacts on cancer survivors may suggest the need for further inclusion of related content on cancer survivor models of holistic wellbeing.

The fourth domain, psychosocial coping strategies, included the following general categories: (e) problem focused coping, (f), meaning focused coping, (g) emotion focused coping, as well as one typical category: (n) cognitive adaptation. The frequencies found within the categories in this domain suggest the importance of various coping strategies in navigating the psychosocial impact of cancer on holistic wellbeing. Notable subcategories within the domain included: "information seeking" (typical; category e), "spiritual and existential coping" (typical; category f), "helping others" (typical; category f) and "avoidance and compartmentalization" (general; category g). While content within these categories does not relate to items in the FACT-G model, the FFWEL-A has a 19-item Coping Self scale with related content (e.g. *I am satisfied with how I cope with stress*). Additionally, items with content related to spiritual coping, content found in category f) meaning focused coping, can be found in questions related to spiritual identity on the FACT-G Essential Self subscale (*I have spiritual beliefs that guide me in my daily life*), whereas items with content related to category (f) problem focused can be found in the FACT-G Creative Self subscale *(When I have a problem, I study my choices and possible outcomes before acting*). In the full model regression in phase 1, the Coping Self scale was the only wellness model scale found to significantly contribute to the full

model. Results from both phases suggest the importance of coping styles as significant factors in cancer survivors' psychosocial wellbeing.

Four notable categories emerged within the fifth domain, impact of cancer on psychosocial wellbeing, including general categories: (h) changes in beliefs, attitudes, and behaviors and (i) relational impacts, as well as the typical category: (o) chronic mental and emotional impacts. Category (h) change in beliefs, attitudes and behaviors, which included six subcategories, notably included data from participant experiences that related heavily to concepts of posttraumatic growth, a widely known concept that refers to the "positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (Tedeschi & Calhoun, 2004, p. 1). Positive factors of emotional wellbeing, including optimism, spirituality, and positive coping styles are strongly correlated with PTG (Shand, Cowlishaw, Brooker, Burney, & Ricciardelli, 2015). The FFWEL-A had some questions with seemingly related content. The chronometric context scale (not included in phase 1 analysis) included questions with related content including: *I am optimistic about the future*, and *I look forward to growing older*. The FACT-G had arguably little-to-no related content with this category, with two possible related items including: *I am able to enjoy life*, and *I am content with the quality of my life right now.* Nevertheless, based upon the frequency of qualitative content found within this category, the inclusion of PTG related content may be particularly appropriate in wellbeing models for cancer survivors in later stages of treatment, or post treatment. Category i) relational impacts covers a range of negative, positive, and neutral impacts from cancer on survivor's interpersonal relationships, the most notable of which were

represented in the typical subcategories of: “improved relational health”, “unsupportive/unhelpful responses from family and friends”, and “negative emotional impact on family and friends”. A handful of questions on both assessments include content that may be related to this category (FACT-G: e.g., *I feel close to my friends*; *My family has accepted my illness*; *I am satisfied with family communication about my illness*; FFWEL-A: e.g., *I have at least one close relationship that is secure and lasting*; *I have at least one person who is interested in my growth and well-being*); however, content on the FACT-G appears to be more relevant as it describes experiences in direct relation to the cancer context. Category (o) chronic mental and emotional impacts included content related cancer survivor experiences of anxiety related to their health and mortality, and included instances where cancer survivors shared explicit fears of recurrence. The FFWEL-A, a non-cancer specific measure, does not include items with explicit content related to this category. The FACT-G includes items with related content such as *I worry about dying* and *I worry that my condition will get worse*.

In response to research question three (*Are current models consistent with the identified salient psychosocial factors in the lived experiences of cancer survivors?*), there appears to be some consistency with the models explored and the self-identified salient psychosocial factors of cancer survivors. The (QoL) FACT-G assessment model included several relevant content areas, and was found to be particularly advantageous in its inclusion of content related to physical wellbeing, social supports, relational impacts, and chronic negative impacts related to anxiety regarding health and mortality. Similarly, while the (wellness) FFWEL-A assessment model was found to have fewer salient factors

of wellbeing specific to cancer survivors, the FFWEL-A included content related to a crucial area of psychosocial wellbeing: psychosocial coping. Additionally, qualitative findings suggest the inclusion of content related to healthcare experiences (with various types of providers), instrumental needs, financial impacts, and factors related to PTG within a cancer survivor model for holistic wellbeing.

Summary

In this chapter, the researcher has provided the results of the statistical analysis computed in Phase 1, the results of the qualitative analysis produced in Phase 2, and has provided an integrative analysis examining the conjunctive results of Phase 1 and 2 in the assessment of multidisciplinary holistic models of wellbeing as they relate to the psychosocial health of cancer survivors.

CHAPTER V

DISCUSSION

Introduction

The purpose of this study was to gain a greater understanding of the psychosocial needs of cancer survivors in order to close current gaps in psycho-oncological care. Psychosocial wellbeing is generally considered to be a dynamic construct, involving multiple inter-related factors also known to impact and be impacted by biomedical wellbeing (e.g., Adler, Page, & The Institute of Medicine, 2008; Forsythe et al., 2013; Lai, Garcia, Salsman, Rosenbloom, & Cella, 2012). In this section, the researcher will discuss the major findings and implications of this study based upon the results presented in Chapter IV, and will explore how the findings relate to relevant research literature. The researcher will also discuss any unexpected findings or conflicting explanations present in the data. Additionally, the researcher will address the limitations of the current study. Lastly, the researcher will summarize implications for theory and practice, and will provide suggestions for future research. The summary will highlight implications for mental and biomedical health practitioners and researchers.

Discussion of the Results

The major focus of this study related to the identification of salient psychosocial factors in the wellbeing experiences of cancer survivors, and the extent to which current disciplinary models of wellbeing accounted for these factors. The results of this study

indicate that current assessment models of wellbeing utilized in biomedical and mental health care are useful tools for assessing the psychosocial needs of cancer survivors. Additionally, wellbeing models from biomedical and counseling perspectives were found to both significantly relate, and to contribute uniquely in explaining depression scores among cancer survivors. However, qualitative results from the study describe a more complex picture of psychosocial wellbeing in cancer survivorship than either of the wellbeing models explored in the quantitative phase. The overall results of this study provide evidence in support of further expansion of wellbeing models utilized in integrated cancer care to better account for the specific psychosocial needs of cancer survivors in the United States. The following paragraphs will further discuss these findings.

The primary researcher utilized depression, a psychosocial factor known to significantly impact a sizable portion of cancer survivors, as a baseline measure of wellbeing model fitness. The results indicated that over half of the participants (n=57%) were experiencing significant levels of depressive symptoms. These high rates demonstrate both the salience of mental health symptoms within cancer survivorship, as well as the utility of depression as a construct for measuring the fitness of wellbeing models for psychosocial assessment among cancer survivors. Both models analyzed in the current study were found to account for a significant ($p < .05$) amount of variance in depression scores, with the QoL model (FACT-G) accounting for 66% of variance in depression scores, and the wellness model (FFWEL-A) accounting for 48% of variance in depression scores. Researchers have criticized current biopsychosocial assessments

utilized currently in medical care for bias towards bio-medical functioning, and have suggested that current models may not adequately capture components related to mental health (Alonso, 2004; Carr, Higinson, & Robinson, 2003; Jacob, 2013). Similarly, the researcher of the current study hypothesized that the biomedical model of wellbeing, QoL, would account for less variance in depression scores among cancer survivors. In the current study, QoL –which is historically measured in oncological care by assessments such as the FACT-G– explained more variance in depression among cancer survivors than a more holistic model of wellbeing, the FFWEL-A. Nevertheless they both contribute to overall variance explained; one should not be discounted over the other.

Integrated results from the qualitative and quantitative phases present a more nuanced lens for understanding the fitness of the assessment models for use in cancer care. Qualitative participants described a range of wellbeing experiences, and collectively highlighted numerous salient wellbeing factors across interviews. At face value, the FACT-G and FFWELA content scales (which included items related to emotional, social, and physical wellbeing) have moderate fitness with the self-described wellbeing experiences of cancer survivors, and may be useful tools in cancer care. However, a more thorough comparison of the results provides more evidence for understanding the unique strengths of each model. For example, while each model includes items related to physical wellbeing, items from the FACT-G relate more closely to cancer survivor's descriptions of their experiences with cancer, such as coping with side effects from cancer treatments (physical factor of wellbeing). Quantitative results indicated analogous findings: whereas the FACT-G subscale measuring physical wellbeing was found to be

significant in the original and combined regression models, the FFWEL-A subscale measuring physical wellbeing was not found to be significant in either regression model. These results are fairly logical, as the FACT-G items were normed on a cancer population (Cella et al., 1993), whereas the FFWEL-A was normed on the general population (Myers & Sweeney, 2005b). Both models show promise as useful tools for assessing the wellbeing of cancer survivors, but the FACT-G appears to more adequately capture the unique physical experiences found within the cancer journey.

Nevertheless, the counseling model of wellness was found to contribute a unique construct to a combined model of holistic wellbeing in cancer survivorship: coping styles. Coping refers to the "cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands or conflicts (Folkman & Lazarus, 1980, p.233)." In the quantitative results, the Coping Self was found to be the only significant FFWEL-A subscale within the combined regression model. The Coping Self subscale included items related to realistic beliefs, stress management, self-worth, and how one spends leisure time (Myers & Sweeney, 2005b). Qualitative results included similar findings: Psychosocial coping strategies emerged as one of the seven domains in the CQR analysis, and included three general categories (problem focused coping, meaning focused coping, & emotion focused coping), one typical category (cognitive adaptation), two variant categories (utilizing pre-existing skills & animal companionship), and one rare category (exercise). The importance of coping that emerged within the current study is supported by other researchers, specifically that coping strategies are significantly linked to psychosocial outcomes in the cancer experience (e.g., Kim, Han, Shaw, McTavish, &

Gustafson, 2010; Lee, Song, Zhu, & Ma, 2017; Zucca, Boyes, Lecathelinais, & Girgis, 2010). Coping strategies are significant predictors of emotional wellbeing among various cancer populations including: breast cancer survivors (Gonzales, Hurtado-de-Mendoza, Santoyo-Olsson, Nápoles, & Nápoles, 2016; Kim et al., 2010), gynecological cancer survivors (Bucholc, Kucharczyk, Kanadys, Wiktor, & Wiktor, 2016), and long-term cancer survivors (Zucca et al., 2010).

Though coping can be described in many ways, coping strategies can be considered *active* (behaviors aimed at facing a problem in order to determine possible viable solutions to reduce the effects of a given stressor) or *passive/avoidant* (behaviors that seek to escape the source of distress without confronting it) (Folkman & Lazarus, 1984). Similarly, coping strategies that are associated with positive psychosocial outcomes are generally considered *adaptive*, whereas coping strategies that are associated with negative psychosocial outcomes are considered *maladaptive* (Zeidner & Saklofske, 1996). Adaptive coping strategies, such as spiritual and existential coping, have been found to be connected to higher levels of emotional wellbeing, whereas maladaptive coping strategies have been linked to lower levels of emotional wellbeing across multiple time points in the cancer experience (Bucholc et al., 2016; Lee et al., 2017; Zucca et al., 2010). The current study has similar findings: while problem focused coping, which involves active coping strategies such as information seeking and proactive behaviors, was present in seven participant interviews, avoidance and compartmentalization (a subcategory of emotion-focused coping) emerged as an important coping strategy for the same seven participants. Experiences coded within the "avoidance and

compartmentalization" subcategory included (a) avoidance of emotional processing of the cancer experience, (b) avoidance in disclosing cancer status to friends and loved ones, and (c) avoidance of cancer related information that might cause negative emotional arousal. Avoidance of emotional processing of the cancer experience has been linked to depression in cancer survivors and is generally considered maladaptive (Lee et al., 2017). Notably, while emotional avoidance and other types of coping are often described in the researcher literature as adaptive or maladaptive within the researcher literature, the qualitative research team in the current study did not organize participant coping experiences as maladaptive vs. adaptive in order to avoid false inferences about participant experiences. However, in addition to positive descriptions of coping outcomes, several participants shared negative outcomes in relation to their chosen coping strategies. One participant described the importance of information seeking as generally helpful, but also shared feeling that he often felt somewhat manic or crazy in his pursuit for medical information. Similarly, some participants described their coping experiences with avoidance and compartmentalization as feeling isolating, while others described their experiences with this coping strategy as necessary for regulating their emotional wellbeing during stressful moments after they received their diagnosis. Since research exploring the specific impacts of various types of coping strategies on cancer survivor wellbeing is nascent, both the qualitative and quantitative findings demonstrate the need for further integration of coping strategies into holistic models of wellbeing in cancer survivorship.

It also is important to examine whether or not the wellbeing models explored include content that did not emerge or were not related to the CQR analysis of the wellbeing experiences shared by cancer survivors. The FACT-G, which was developed with cancer patients and oncologists alike (Cella et al., 1993), does not appear to include model content that was unrelated to the CQR results. Conversely the FFWEL-A model, which was not developed for use with cancer populations, cannot be so easily analyzed. On one hand, the model includes several scales that were not found to be significant predictors of depression within the sample; namely the Creative Self, Essential Self, and Physical Self subscales. Yet, the presence or absence of depressive symptomology does not singularly equate with positive or negative wellbeing. For example, though items such as "My cultural background enhances the quality of my life (Essential Self subscale; Myers & Sweeney, 2005b)" were not predictive of depression within the current sample, researchers have implicated cultural identity as a critical factor in various dimensions of wellbeing among cancer survivors (e.g., Bowen, Singal, Eng, Crystal, & Burke, 2003; Hamilton et al., 2013; Sussner, 2011; Ussher, Rose, & Perz, 2017). It would be illogical to infer that a single interview, or any number of standardized assessments, could capture every factor that contributes to and comprises wellbeing for an individual person. Moreover, as wellbeing is a multifaceted, holistic construct that is known to vary according to individual subjective realities, a one-size-fits-all model is an unrealistic goal. The researcher sought to identify common salient factors of psychosocial wellbeing for the purpose of improving theory, assessment, and practice in psychosocial cancer care. By the same token, however, it may be critical to assess and intervene for less-common

salient psychosocial factors that impact cancer survivors, should they arise. For example, in the qualitative sample, one participant with a form of bile duct cancer that is known to be particularly aggressive and deadly reported several experiences that were less common among the sample: increased traumatization as a result of losing several members of his support group to bile duct cancer, finding a scarcity of information and resources for his cancer type, and difficulties finding knowledgeable medical providers. Although this participant's experiences are less common among the sample, the participant described these experiences as having a significant impact on his wellbeing. These and other examples in the qualitative findings highlight the tensions between emphasis on common factors, and making space for individualized assessment in psychosocial cancer care.

Additionally, salient themes emerged within the qualitative findings that are not present in either model. As discussed in the previous chapter, neither model of wellbeing explored in the current study provided intentional assessment of PTG. A major finding of the current study relates to the importance of positive psychosocial growth, or outcomes consistent with post-traumatic growth (PTG), as significant factors in the psychosocial experiences of cancer survivors. Seven of the eight participants in the CQR analysis highlighted experiences consistent with PTG, as highlighted by narratives illuminating experiences related to increased appreciation for life, recognition of new life possibilities, and spiritual and existential development. These findings are consistent with previous studies that have explored the prevalence and known correlates of PTG in cancer survivors (e.g., Connerty & Knott, 2013; Shand, Cowlishaw, Brooker, Burney, & Ricciardelli, 2015, Sim, Lee, Kim, & Kim, 2015). A 2013 qualitative analysis of PTG

among cancer survivors indicated that PTG is often the result of several complex psychosocial factors (Connerty & Knott, 2013). Notably, authors of the study found that factors such as strong social support, maintaining preventative health behaviors, and lifestyle changes aimed at improving existential meaning significantly contributed to PTG. Similarly, researcher findings from Shand et al. (2015) suggest a strong correlation between cancer survivor's PTG and factors such as optimism, spirituality, and positive coping styles. Qualitative results from the current study found consistently high rates of factors known to be associated with PTG, as demonstrated by general or typical categories (or subcategories) in areas such as social support, improved relational health, increase in positive health behaviors, and various types of positive coping including spiritual and existential coping and cognitive adaptation (includes optimism). Furthermore, meta analysis of PTG and symptoms related to post-traumatic stress, depression, and anxiety have indicated that PTG may often be present for cancer survivors despite the presence of symptoms related to negative psychosocial wellbeing (Shand et al., 2015). Despite a prevalence rate of 37.5% for significant depressive symptomology in the qualitative sample, 87.5% of qualitative participants endorsed experiences indicative of PTG and all participants described experiences known to correlate with PTG. These findings suggest that PTG does not exist on a spectrum opposite of negative psychosocial factors; rather, PTG may be a critical positive psychosocial factor in the wellbeing experiences of cancer survivors regardless of the presence of negative mental health symptomology. Furthermore, PTG is thought to provide a buffering effect on negative psychosocial experiences (Connert & Knott, 2013).

Findings from this study, in conjunction with previous literature, suggest that inclusion of PTG-specific factors within holistic models of wellbeing may be particularly beneficial in cancer survivor populations. Cancer survivors in later stages of treatment or in remission may particularly benefit from assessment for PTG, as these individuals will have had more time to experience psychological change as a result of their cancer experience. Similarly, intentional assessment of factors known to be predictive of PTG may improve psychosocial screening and care for cancer survivors in earlier stages of the cancer journey.

Another major finding in the current study related to the importance of cancer survivor's perceived experiences with health providers and health settings. Among the qualitative sample, all of the participants described their experiences with various health providers and settings as critical to their wellbeing during treatment, and beyond. Participants also described their experiences with a range of health providers, including primary care providers, oncologists, nurses, social workers, mental health counselors, genetic counselors, psychologists, physical therapists, and nutritional counselors. As discussed in chapter four, neither model includes assessment for satisfaction with care or the health provider relationship, although the FACT-G has included related content in previous versions (Cella et al., 1993). Nevertheless, participants' experiences included several themes that illuminate common factors in both positive and negative care experiences. All participants reported more positive experience, although five participants shared having negative experiences. The majority of participants that described negative experiences initially experienced negative reactions to their provider

skill or personality, and were able to find more satisfying care after switching providers. However, a more useful understanding of these experiences may be found in common themes, as opposed to chronology. Negative experiences of care, whether medical or psychosocial, were often described in connection with feeling a sense of condescension or antipathy from care providers. Participants described being treated as ignorant, being kept out of the loop on medical decision making, or noticing a lack of attention to the psychosocial impacts of cancer as common themes in negative care experiences. Conversely, positive care experiences included themes of feeling they were intentionally informed about medical options, physical side effects, and psychosocial impacts by providers, feeling their treatment decisions were valued and respected, and provider recognition of their emotional reactions to the cancer experience. Participants noted specific appreciation for providers that spent time getting to know them, or encouraged them to share their needs and questions. Several participants' highlighted favorable perceptions for care settings that provided easy access and referrals to a variety of care services, such as mental health counseling, instrumental resources, and genetic counseling. Integrated care settings were described favorably, whereas settings with fewer care options were described less favorably. These findings are in line with the underlying premise of this study: cancer patients receive better care when their holistic needs are attended to within integrated models of care. The importance of patient satisfaction with care is one of the most important care outcomes, in addition to QoL (Kleeberg et al., 2005). Although results on the exact relationship between QoL (or wellbeing) and satisfaction with care are mixed, higher QoL scores have been associated

with higher satisfaction of care (Brédart, et al., 2001). It has been hypothesized that variance in patient expectations of clinical care, the nature and stages of various cancer diagnosis, and variance in measures of patient satisfaction in relation to their assessment of informational and psychosocial care expectations may greatly contribute to current difficulties in assessing the nature of the relationship between patient satisfaction and QoL (Wong & Fielding, 2008).

Relatedly, *receipt of information* emerged as a consistent theme within the qualitative participant's shared wellbeing experiences. Participants repeatedly highlighted the importance of being informed about their diagnosis and treatment as significant factors to their ability to cope during the active treatment stage. While the majority of participants sought this information from providers, several participants highlighted the importance of support groups and cancer foundation postings as other important sources of information. Interestingly, participants with previous experience working in healthcare settings, or with family members in healthcare settings, highlighted "insider knowledge" as important coping tools for navigating the cancer experience. Other studies have indicated the importance of family and friends as important sources of information for many cancer patients (Mills & Davidson, 2002). Overall, these experiences may suggest the importance of information as a tool for active coping among cancer survivors. Receipt of information also was found to be an important theme on the positive/negative care continuum. Researcher literature highlights the importance of informational support for cancer survivors, with multiple studies indicating a need for improvements in informational support and patient-provider communication (Bayram, Durna, & Akin ,

2014; Brédart et al., 2001; Kleeberg et al., 2005). Although neither model explored in the current study addresses the importance of informational support, qualitative findings support the inclusion of informational support within a holistic model of wellbeing in cancer survivorship.

Lastly, the qualitative data included several themes around the emergence of functional and financial impacts during the cancer journey, and the resultant importance of social and financial supports to meet emerging needs. A cancer diagnosis often includes considerably high medical costs, with average individual expenditures ranging from $6,000-$10,000, depending on insurance type and care needs (American Cancer Society Action Network, 2017). While costs for radiation, surgery, and pharmacological treatments can be substantial, cancer patients often experience other related costs for treatment, including home health care and travel-related expenses to get to treatment facilities (Brooks, Wilson, & Amir, 2011). Additionally, cancer survivors that are employed often experience a loss of productivity at work, or a total loss of employment and work related benefits (Bradley, Neukarm, Luo, & Schenk, 2009). Other indirect costs that contribute to financial burden among cancer survivors include domestic costs, such as the need for childcare or domestic help during active treatment, and other medical-related costs such as medical equipment, special foods, and nutritional supplements (Brooks et al., 2011). In short, the cancer experience often includes a variety of financial and functional impediments.

In the current study, several participants highlighted the importance of various friends and family members providing assistance in meeting some of these needs,

including help with transportation, domestic tasks at home, and child care. Similarly, participants described having various degrees of financial resources, and highlighted family savings, inheritances, and other sources of family income as significant to their wellbeing during the cancer experience. The availability of instrumental resources within an individual's social structure, referred to as *social capital* in the researcher literatue (Van Der Gaag & Webber, 2008), may prove to be a significant buffer for financial burden associated with cancer. Conversely, individuals without sources of social capital may experience higher degrees of financial burden. Factors such as low income, chemotherapy treatment, and living in rural areas have been associated with a greater impact of financial burden (Brooks et al., 2011). Relatedly, several participants in the current study reported living in a rural area as a significant obstacle during their cancer experience. Insurance has also been found to be a significant asset in overcoming cancer-related financial burden (American Cancer Society Cancer Action Network, 2017; Timmons, Gooberman, & Sharp, 2013). In the current sample, several participants highlighted their gratitude for insurance in covering medical costs, and noted that they may have been unable to pay for their medical bills without insurance. Two participants noted their concern for rising health costs, and described that their experience with cancer had significantly changed their economic ideologies in support of a universal healthcare system.

Notably, nearly all participants in the study commented upon concern for the extreme financial burden of cancer, regardless of their personal level of cancer-related financial burden. These responses are unsurprising, as researchers and healthcare

providers are increasingly recognizing the financial burden of cancer. Furthermore, costs are projected to rise. In the United States, analysts project a national cost-of-cancer increase of $157.77 billion by 2020 (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011). These costs are expected to translate to higher individual expenses, with lower-income and non-insured patients facing the highest degree of financial burden (American Cancer Society Action Network, 2017).

Furthermore, financial burden of cancer is known to extend to post-treatment survivorship, resulting in long-term negative impacts (Menses, Azuero, Hassey, McNees, & Pisu, 2012). Although the overall impact of financial burden remains poorly understood, researchers have linked financial burden of cancer with several important psychosocial factors. A recent study on the impact of financial burden of cancer on survivor's quality of life (measured from a participant sample of 2,108 cancer survivors) found that the degree to which cancer caused financial problems was the strongest independent predictor of quality of life (Fenn et al., 2014). Similar studies have found cancer-related financial burden to be consistently associated with poorer quality of life (Menses et al., 2012), PTG (Balfe et al., 2016; Ho et al., 2011), and increased rates of depression, anxiety, and general distress (Sharp, Carsin, & Timmons, 2013). Results from the current study, and additional researcher findings, suggest that cancer-related sources of financial burden may be a significant, and increasingly important facet of cancer survivor wellbeing. Neither of the wellbeing models explored in the current study included content related to the construct of cancer-related financial burden, contrary to

emerging evidence of its salience. Implications for this, and other discussed findings, are discussed below.

Implications

Implications for Theory

The findings from the current study support the utility of an interdisciplinary approach to refining of theories of holistic wellbeing. While the explored models were generated from differing theoretical approaches to conceptualizing wellbeing (e.g. biomedical vs. counseling), the results indicated that the models both contributed unique constructs to the full model, and included more shared than unique variance. These results suggest enough commonality between models for further exploration between mental and biomedical researchers alike. Researchers from multiple fields have suggested the importance of interdisciplinary investigation and generation of wellbeing models and theory, with the intent of improving integration of wellbeing factors within theoretical models (Carr et al., 2003; Chambers et al., 2014; Lavdaniti & Tsitsis, 2015; McGrady & Moss, 2013). Furthermore, interdisciplinary exploration of theoretical wellbeing, in oncological or other health populations, may prove critical in refining a broad range of providers' understandings of the complex interactions between biomedical and psychosocial constructs. Specifically, findings from the current study suggest the utility of increased integration of biomedical models of disease and physical impacts, and counseling psychology theories of PTG and coping. Additionally, further development of theoretical models of wellbeing may similarly benefit from increased incorporation of economic context. In the current study, neither model accounted for the significant

impact of cancer-related financial burden. Financial burden is closely tied with both individual sociopolitical contexts within a larger societal structure, as well as the economic landscape of health institutions. Modern theories of holistic wellbeing in the cancer context must account for rising healthcare costs (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011), and resultant impact on individual wellbeing.

The findings in this study have several pointed implications for wellness theory within the counseling profession. The results of the current study indicate that general wellbeing models utilized by the counseling profession may have less utility in capturing the wellbeing needs of cancer survivors than more disease-specific models. The wellness model utilized in the current study was developed from a counseling lens (Myers, Sweeney, & Witmer, 2000), and was found in this study to provide a uniquely significant construct for predicting wellbeing that is closely aligned with the realm of counseling and psychology: coping styles. However, the assessment model lacks a specific biophysical context, and resultantly does not capture the unique context of the psychosocial experiences of cancer survivors. Similarly, the impact of physical health effects on holistic wellbeing is direly underrepresented in counseling literature and theory. As counselor researchers and educators continue to improve theoretical models and philosophies for understanding the wellbeing needs of specific health populations, such as cancer survivors. Integration of biomedical constructs, and utilization of literature from a variety of health-related fields such as oncology, epidemiology, and public health, may prove meaningful to the development of counseling theories of wellness and wellbeing. Furthermore, these aims are consistent with the philosophical underpinnings

of the counseling wellness model: to promote wellness and prevention over the lifespan, to integrate theoretical perspectives from a variety of disciplines including traditional counseling and psychology disciplines *as well as* biomedical health disciplines, and to conceptualize wellness as the active pursuit of optimal health and wellbeing in which "body, mind, and spirit" are integrated (Myers et al., 2000).

Implications for Practice

Findings from the study implicate suggestions for practice for biomedical and mental health providers alike. As discussed in previous chapters, incidence of cancer is expected to rise 70% over the next two decades (World Health Organization, 2015), while advancements in biomedical treatments of cancer have similarly contributed to increase rates of cancer survivorship (Adler, Page, & Institute of Medicine, 2008). These numbers suggest a general rise in cancer survivorship, and increased need for meaningful care of medical and psychosocial needs of cancer survivors.

Professionals across multiple health professions have written simultaneously of the general effectiveness of oncological health care, as well as the failure of cancer care in addressing psychosocial needs of cancer survivors (Adler et al., 2008; Chambers, Hutchinson, Clutton, & Dunn, 2014; Grassi & Riba, 2014; Holland, Watson, & Dunn, 2011). Assessment of psychosocial needs has been highlighted as a key intervention point for improving the identification of psychosocial needs and referrals to psychosocial treatment (Adler et al., 2008). The current study explored the effectiveness of two disciplinary assessment models of biopsychosocial wellbeing, as biopsychosocial assessment is considered particularly appropriate for addressing the needs of health

populations such as cancer survivors (Shapiro et al., 2001; Hatala, 2012; Alonso, 2004). Both models appeared to provide a reasonable baseline assessment of psychosocial needs of cancer survivors, although suggested improvements to assessment models have been highlighted. Notably, the FACT-G model was found to account for the greatest amount of variation in participant depression scores, and included several areas of salient content in comparison to the qualitative results of cancer wellbeing experiences. Although medical models of biopsychosocial wellbeing such as QoL have been criticized for over-emphasis on biomedical factors, and possibly masking an underlying biomedical approach (Alonso, 2004; Hatala, 2012), the FACT-G assessment model of QoL may be a useful tool for medical providers in assessing psychosocial and general wellbeing in cancer survivors. While the FACT-G may be considered the gold standard for QoL assessment in cancer care, general utilization rates of the FACT-G within medical contexts is unknown. As medical providers are often the entry point into specialized health services such as mental health counseling, increased utilization of the FACT-G may be beneficial in closing psychosocial gaps in care.

Participants in the qualitative phase highlighted the importance of provider interactions and satisfaction with care. Common themes among the positive and negative care continuum included receipt of information, feeling respected by providers, recognition of emotional experiences and needs, and feeling included in treatment decisions. While the exact relationship between patient satisfaction and cancer survivor wellbeing is unclear, improvements in patient-provider relationships and communication continue to be highlighted as a need throughout the literature, particularly in relation to

patient's psychosocial needs (e.g., Adler et al., 2008; Forsythe et al., 2013; Söllner et al., 2001).

Similarly, as providers face continued limitations in time for patient visits (Adler et al, 2008; Bendix, 2013), and are generally less trained to recognize psychosocial needs (Mitchell, Hussain, Grainger, & Symonds, 2011; Mitchell, Rao, & Vaze, 2011), medical settings should utilize the expertise of a wide range of health professionals for meeting the holistic needs of cancer survivors. Robust screening tools, such as the FACT-G, may serve as a significant first step. However, as the results of this study indicate, psychosocial needs vary significantly by individual. Mental health professionals are more appropriately trained to assess the variety of factors that contribute to psychosocial wellbeing, and should be increasingly incorporated into integrated care settings. A lack of psychosocial professionals has also been noted as a barrier within oncological care psychosocial professionals within cancer programs (Adler et al., 2008). Participants in the qualitative sample reported positive attitudes towards integrated care settings, and noted positive experiences with nurses, social workers, and counselors alike. An integration health professions approach to closing psychosocial gaps in oncological care may prove more feasible and effective than a myopic focus on provider assessment, and is consistent with researcher suggestions (American Psychological Association, 2016; Evans et al., 2013; Leach, 2006).

Findings from the current study have additional implications for mental health providers. Co-morbidity of mental health diagnosis among cancer survivors remains high (e.g., Derogatis et al., 1983; Honda & Goodwin, 2004; Massie & Holland, 1990; Nakash

et al., 2014). Participants in the current sample demonstrated high rates of depression (57.1%) Additionally, a diagnosis of cancer has been shown to have significant impacts on the immediate family members of cancer survivors (e.g., Balfe et al., 2016; Livneh & Antonak, 2005; Rolland, 1994; Rolland, 2005). Participants also highlighted various incidences of positive and negative impacts from cancer on their immediate social structures. Rising rates of cancer survivors and cancer incidence, in addition to high rates of co-morbid mental health needs among cancer survivors suggest the need for well-trained mental health professionals in meeting the mental health needs of the cancer survivor's and their families. Additionally, results from the current study indicate that cancer survivor's may benefit from counseling and psychoeducation to promote positive coping skills, and to highlight cancer survivor's experiences of PTG as means of buffering some of the negative psychosocial impacts of cancer.

However, there exists limited standards for integrating psychosocial and biomedical needs in most mental health fields. As previously discussed in chapter two, mental health educators have questioned the preparedness of psychologist and counseling students to conceptualize and attend to the integrated biopsychosocial needs of clients dealing with significant health decline (Barden, Conley, & Young, 2013; Diamond 2007). Although the findings of the current study did not specifically relate to mental health provider training, the counseling model of wellness was found to be sorely lacking in the biomedical context necessary to frame the wellbeing experiences of cancer survivors. Improvements in mental health education and training should include an increased focus on the impact of biomedical health on holistic wellbeing, as well as increased utilization

of wellbeing assessment models that address biomedical and psychosocial factors, in order to better meet need the holistic needs of their clients.

Future Research

The current study provided the first exploration of a counseling model of wellbeing, the wellness model, with a biomedical model of wellbeing, QoL. Initial results indicate strong connections between models, as well as unique contributions from each model towards a more holistic biopsychosocial model of wellbeing among cancer survivors. The quantitative results, in addition to results from the qualitative analysis, implicated several factors worthy of further investigation.

As previously discussed, the wellness model was found to have limited applicability to the cancer-specific impacts on the wellbeing of cancer survivors. The counseling profession cites wellness as their foundational paradigm (Myers, 1992). With increasing rates of cancer incidence and survival, in addition to high rates of mental health needs, counselor researchers may greatly benefit from continued research into wellness assessment for cancer survivors. The development of a wellness assessment model for cancer survivors also may prove beneficial in advancing counselor training and readiness for working with cancer survivorship populations. The results of the current study may serve as a beneficial starting point for this endeavor.

Results from the qualitative and quantitative phase of the study indicated the importance of coping styles in the cancer context. While future biopsychosocial wellbeing models utilized in cancer care would benefit from the inclusion of coping-related items, further research is also needed to identify common coping styles and their

outcomes among cancer survivors. Although coping strategies are often found to improve wellbeing, coping strategies may also include negative effects, or may be maladaptive altogether (e.g. obsessively researching one's diagnosis to the point hysteria). Coping styles may prove to be critical moderating factor of psychosocial wellbeing within the cancer context, and are worthy of further investigation.

Findings from the study also suggest several key areas for future research among a variety of health researchers. The presence of factors consistent with PTG within the qualitative model suggest the salience of PTG and other positive factors as crucial for inclusion within a model of holistic wellbeing in cancer survivorship. As PTG is thought to provide a buffering effect on negative psychosocial experiences (Connerty & Knott, 2013), further investigation of PTG in the experiences of cancer survivors may shed light on counseling interventions for promoting factors known to be associated with PTG among cancer survivor populations.

Additionally, qualitative participants in the current study highlighted the salience of cancer-related financial burden among cancer survivors. The experiences of the qualitative participants in the current study, as well as researcher literature, indicate the salience of cancer-related financial burden in connection with obtaining cancer-related medical care (e.g., American Cancer Society Action Network, 2017), cancer-related impact on functional wellbeing (e.g., Bradley et al., 2009), emotional wellbeing (e.g., Sharp, Carsin, & Timmons, 2013), and overall lower quality of life (e.g., Menses et al., 2012). The overall impact of financial burden on cancer wellbeing is currently thought to be poorly understood. Continued investigation into the impact of financial burden on

cancer survivor's holistic wellbeing may be a paramount research priority, given the evidence for impact on wellbeing in conjunction with projected rising rates of cancer-related healthcare costs (American Cancer Society Action Network, 2017; Mariotto et al., 2011).

Limitations

As with all studies, the current study had several limitations. The study was focused on understanding significant psychosocial factors that impact holistic wellbeing of cancer survivors. Studies examining wellbeing or quality of life, related multi-factor concepts of health that include subjective and objective dimensions, are known to be intrinsically limited in terms of generalizability, as neither are considered a static trait and are known to vary greatly by individual (Carr et al., 2003; Moons, Budts, & De Geest, 2006; Sirgy, 2012). Nevertheless, refinement of biopsychosocial assessment models to capture psychosocial needs within oncological care remains a top research priority (Adler et al., 2008).

There were also limitations to the proposed study in relation to the sample. This study utilized self-reported feedback from cancer survivors who were in full or partial remission, and therefore were not currently experiencing cancer related effects associated with active treatment. Although participants were be asked to reflect upon their experiences during cancer treatment in Phase 2, selective memory bias may impact study findings. As the topic of the study relates to psychosocial factors of wellbeing, participant responses may also be limited by their own self-awareness of their mental and emotional wellbeing. Resultantly, generalizability of study findings to active status cancer survivors

may also be limited as a result of the sampling methods. However, utilization of active-status cancer participants is often cautioned against, as research studies may cause them additional strain, and may be difficult to recruit (Akker, Deckx, Vos, & Muth, 2016). Generalizability of the study findings may be limited according the cultural representation of the sample, as 81% of the current sample identified as white. Findings from the current study may not adequately translate to the wellbeing experiences of minority cancer survivors. Finally, within the current sample, 57.1% of cancer survivors indicated having significant depressive symptomology. These rates are considerably higher than the projected 20-30% rate of depression of cancer survivors (Honda & Goodwin, 2004; Irwin, Henderson, Knight, & Pirl, 2014). While the higher rate of depression in the current sample is not easily explainable, the use convenience-sampling methods utilized in the current study may have drawn in participants that felt more eager to share about their challenges in the cancer experience, and thusly may have been more likely to have experienced significant psychosocial cancer impacts such as depression.

Quantitative results in this study may also be limited by the chosen assessment measures. The utilized model of wellness, as measure by the FFWEL-A, has not been extensively utilized in health populations, and has never been used in cancer-related research. Additionally, the FACT-G assessment model of QoL was designed for use among active-status cancer patients, and may be less valid for measuring QoL among cancer survivors in remission. However, the FACT-G is commonly used in studies of cancer survivors in remission (e.g., Ashing-giwa, Kim, & Tejero, 2008; O'leary, Diller, & Recklitis, 2007), and is considered among the most valid QoL measures utilized in

oncology research. Furthermore, the disciplinary lens and structures of the chosen assessments may have impacted the quantitative findings; whereas the FFWEL-A was created from a counseling perspective and includes a high number of items, the FACT-G and the CES-D-10 were both created from a medical perspective and were intended to be brief assessment measures. Similarities between the structures of the FACT-G and the CES-D-10 may have contributed to higher rates of shared variance between the respective measures.

The primary researcher, and the qualitative research team, attempted to provide an unbiased representation of the wellbeing of cancer survivor experiences described in this study. While the appropriate steps were taken to ensure the rigor of the methodology, trustworthiness is often a consideration in qualitative research. Congruent with the standards of CQR (Hill, et al., 2005), the qualitative research team incorporated a rigorous research structure including bracketing assumptions prior to analysis, utilizing an external auditor to ensure the quality of the analysis, and a consensual decision making process in the creation of all domains, categories, and subcategories. Nevertheless, as the study is the doctoral dissertation of the primary researcher, the primary researcher took the lead by obtaining the participant sample from Phase 1 participants, interviewing the participants, and transcribing the semi-structured interviews. Additionally, during the consensual analysis, the primary researcher experienced a greater bias towards the data due to higher level of experience with the data, as well as greater exposure to the relevant researcher literature. The other team members gave consistent and thoughtful contributions to analysis, but the primary

researcher may have had a greater influence on the data analysis than other research team members.

Conclusion

In this study, the researcher utilized quantitative and qualitative results to identify salient psychosocial factors within the wellbeing experiences of cancer survivors. Additionally, this study explored the extent to which biomedical and counseling models of wellbeing captured salient psychosocial factors in cancer survivorship, as well as the commonality of the disciplinary models. Integrated findings reveal several areas for continued improvement of biopsychosocial models utilized in cancer care; namely further exploration and inclusion of items related to coping styles, PTG, patient satisfaction with healthcare providers, and cancer-related financial burden. Additionally, in closing current gaps in psychosocial care for cancer survivors, it may be imperative for increased recognition of multidisciplinary perspectives. Biomedical and mental health providers alike bring meaningful perspectives to a biopsychosocial framework, and may only be strengthened through intentional integration of researcher and practice methods. Finally, it is imperative that cancer survivor's perceptions of their wellbeing experiences are increasingly sought out and utilized to improve psychosocial cancer care. Wellbeing is, by definition, a subjective construct: who understands the impact of cancer as profoundly as those who experience it? Continued dialogue and integration between medical, mental health, and patient perspectives of holistic wellbeing in cancer survivorship will enhance, and hopefully evolve, the current state of psychosocial care of cancer survivors.

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APPENDIX A

RECRUITMENT AND CONSENT FORMS

Page

INFORMED CONSENT PHASE 1 (SOCIAL MEDIA RECRUITMENT)

UNIVERSITY OF NORTH CAROLINA AT GREENSBORO

CONSENT TO ACT AS A HUMAN PARTICIPANT

Project Title: *Significant Psychosocial Factors Related to Holistic Wellbeing Among Cancer Survivors*

Principal Investigator and Faculty Advisor: Hallie Sylvestro, M.Ed., Principal Investigator; Keith Mobley, PhD, Faculty Advisor

What is this study about? You are being asked to take part in a research study designed to learn more about how mental health and medical professionals can best support the psychosocial needs of cancer survivors. Psychosocial needs include aspects of wellbeing such as mental, emotional, spiritual, and social health. This study will consist of the completion of an electronic survey packet that will contain a demographic form and three questionnaires. The questions within the survey will pertain to different aspects of your wellbeing in cancer survivorship.

The purpose of this study is to learn more about psychosocial factors that play a critical role in general wellbeing or quality of life among cancer survivors. This information will be useful in guiding mental health and medical professionals in the improvement of psychosocial care of cancer survivors throughout the cancer journey.

Details about this study are discussed in this consent form. It is important that you understand this information so that you can make an informed choice about being in this research study. If you have any questions about this study at any time, you should ask the researchers named in this consent form. Their contact information is below.

Who qualifies for this study? Participants in this study should meet the following criteria: 1) are at least 18 years old; 2) are currently in partial or full remission of cancer; 3) are within three years of receiving a cancer diagnosis (any stage/type); 4) underwent surgery, radiation, and/or chemotherapy during the course of cancer treatment.

What will you ask me to do if I agree to be in the study? The study will ask you to complete a demographics questionnaire and three surveys. It is estimated to take approximately 20-40 minutes to complete the electronic survey packet. At the end of this study you will be provided with an opportunity to volunteer to participate in a semi-structured interview by Hallie Sylvestro, the primary investigator, about cancer survivor's perspectives on wellbeing during and after cancer treatment.

What are the risks to me? The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risk to participants. The minimal risks may include emotional reactions to questions on the surveys and are not expected to require medical or psychological treatment. Please know you have the option not to respond to any questions that cause you to feel uncomfortable

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8/29/16

or emotionally distressed.

If you feel any emotional distress, you are encouraged to seek counseling from a qualified professional. The following online database of counselors can assist you in locating a qualified professional: http://www.nbcc.org/CounselorFind.

If you have questions, want more information or have suggestions, please contact Hallie Sylvestro at (336) 334-3423 or email at hmkuruck@uncg.edu, or faculty advisor Keith Mobley, PhD, at k_mobley@uncg.edu. If you have any concerns about your rights, how you are being treated, concerns or complaints about this project or benefits or risks associated with being in this study please contact the Office of Research Integrity at UNCG toll-free at (855)-251-2351.

Are there any benefits to society as a result of *me* taking part in this research? Your participation may help mental health and medical professionals better understand, assess, and support the psychosocial needs of cancer survivors. It is hoped the research will lead to a better understanding of improved psychosocial treatment and resources within cancer care to improve the wellbeing of cancer survivors and their families.

Are there any benefits to *me* for taking part in this research study? There are no direct benefits to participants in this study.

Will I get paid for being in the study? Will it cost me anything? There are no costs to you for participating in this study. The primary researcher will donate $1 for each completed electronic survey packet to the LiveStrong Foundation, a charitable foundation that supports research, education, and support services for individuals who have experienced cancer (LiveStrong.org).

How will you keep my information confidential? The information you share will be kept confidential. Confidential data collection procedures have been put into place. The Qualtrics online web tool meets the strictest confidentiality standards and is in full compliance with HIPAA. No information collected will have identifying information attached, unless you elect to volunteer for a post-survey interview and provide an email address. These email addresses will be kept until the interviews are completed, at which point all email addresses will be removed from the database.

All information obtained from surveys will be stored on a password-protected computer. All information obtained in this study is strictly confidential unless disclosure is required by law.

Please also note that absolute confidentiality of data provided through the Internet cannot be guaranteed due to the limited protections of Internet access. Please be sure to close your browser when finished so no one will be able to see what you have been doing.

What if I want to leave the study? You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data that has been collected be destroyed unless it is in a de- identifiable state. The investigators also have

the right to stop your participation at any time.

What about new information/changes in the study? If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

Voluntary Consent by Participant: By checking this box f you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document, meet the study criteria, and are agreeing to participate in this study. All of your questions concerning this study have been answered. You are encouraged to print this page for your records before proceeding.

Approved IRB
8/29/16

INFORMED CONSENT PHASE 1 (QUALTRICS RECRUITMENT)

UNIVERSITY OF NORTH CAROLINA AT GREENSBORO CONSENT TO ACT AS A HUMAN PARTICIPANT

Project Title: *Significant Psychosocial Factors Related to Holistic Wellbeing Among Cancer Survivors*

Principal Investigator and Faculty Advisor: Hallie Sylvestro, M.Ed., Principal Investigator; Keith Mobley, PhD, Faculty Advisor

What is this study about? You are being asked to take part in a research study designed to learn more about how mental health and medical professionals can best support the psychosocial needs of cancer survivors. Psychosocial needs include aspects of wellbeing such as mental, emotional, spiritual, and social health. This study will consist of the completion of an electronic survey packet that will contain a demographic form and three questionnaires. The questions within the survey will pertain to different aspects of your wellbeing in cancer survivorship.

The purpose of this study is to learn more about psychosocial factors that play a critical role in general wellbeing or quality of life among cancer survivors. This information will be useful in guiding mental health and medical professionals in the improvement of psychosocial care of cancer survivors throughout the cancer journey.

Details about this study are discussed in this consent form. It is important that you understand this information so that you can make an informed choice about being in this research study. If you have any questions about this study at any time, you should ask the researchers named in this consent form. Their contact information is below.

Who qualifies for this study? Participants in this study should meet the following criteria: 1) are at least 18 years old; 2) are currently in partial or full remission of cancer; 3) are within five years of receiving a cancer diagnosis (any stage/type); 4) underwent surgery, radiation, and/or chemotherapy during the course of cancer treatment.

What will you ask me to do if I agree to be in the study? The study will ask you to complete a demographics questionnaire and three surveys. It is estimated to take approximately 25-60 minutes to complete the electronic survey packet. At the end of this study you will be provided with an opportunity to volunteer to participate in a semi-structured interview by Hallie Sylvestro, the primary investigator, about cancer survivor's perspectives on wellbeing during and after cancer treatment.

What are the risks to me? The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risk to participants. The minimal risks may include emotional reactions to questions on the surveys and are not expected to require medical or psychological treatment. Please know you have the option not to respond to any questions that cause you to feel uncomfortable

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or emotionally distressed.

If you feel any emotional distress, you are encouraged to seek counseling from a qualified professional. The following online database of counselors can assist you in locating a qualified professional: http://www.nbcc.org/CounselorFind.

If you have questions, want more information or have suggestions, please contact Hallie Sylvestro at (336) 334-3423 or email at hmkuruck@uncg.edu, or faculty advisor Keith Mobley, PhD, at k_mobley@uncg.edu. If you have any concerns about your rights, how you are being treated, concerns or complaints about this project or benefits or risks associated with being in this study please contact the Office of Research Integrity at UNCG toll-free at (855)-251-2351.

Are there any benefits to society as a result of *me* taking part in this research? Your participation may help mental health and medical professionals better understand, assess, and support the psychosocial needs of cancer survivors. It is hoped the research will lead to a better understanding of improved psychosocial treatment and resources within cancer care to improve the wellbeing of cancer survivors and their families.

Are there any benefits to *me* for taking part in this research study? There are no direct benefits to participants in this study.

Will it cost me anything? There are no costs to you for participating in this study.

How will you keep my information confidential? The information you share will be kept confidential. Confidential data collection procedures have been put into place. The Qualtrics online web tool meets the strictest confidentiality standards and is in full compliance with HIPAA. No information collected will have identifying information attached, unless you elect to volunteer for a post-survey interview and provide an email address. These email addresses will be kept until the interviews are completed, at which point all email addresses will be removed from the database.

All information obtained from surveys will be stored on a password-protected computer. All information obtained in this study is strictly confidential unless disclosure is required by law.

Please also note that absolute confidentiality of data provided through the Internet cannot be guaranteed due to the limited protections of Internet access. Please be sure to close your browser when finished so no one will be able to see what you have been doing.

What if I want to leave the study? You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data that has been collected be destroyed unless it is in a de-identifiable state. The investigators also have the right to stop your participation at any time.

Approved IRB
5/2/17

What about new information/changes in the study? If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

Voluntary Consent by Participant: By checking this box you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document, meet the study criteria, and are agreeing to participate in this study. All of your questions concerning this study have been answered. You are encouraged to print this page for your records before proceeding.

☐Yes, I have read and understood the consent form and voluntarily consent to participate in this study

☐No, I do not wish to participate in this study.

Approved IRB
5/2/17

INFORMED CONSENT PHASE 2

CONSENT TO ACT AS A HUMAN PARTICIPANT

Project Title: *Significant Psychosocial Factors Related to Holistic Wellbeing Among Cancer Survivors*

Principal Investigator and Faculty Advisors: Hallie Sylvestro, M.Ed., Principal Investigator; Keith Mobley, PhD, Faculty Advisor

What is this study about? You are being asked to take part in a research study designed to learn more about how mental health and medical professionals can best support the psychosocial needs of cancer survivors. Psychosocial needs include aspects of wellbeing such as mental, emotional, spiritual, and social health. This is a follow up from the electronic survey you previously participated in, and you are being contacted due to your indicating interest in further participation in an interview about your experiences with cancer survivorship.

The purpose of this study is to learn more about psychosocial factors that play a critical role in general wellbeing or quality of life among cancer survivors. This information will be useful in guiding mental health and medical professionals in the improvement of psychosocial care for cancer survivors throughout the cancer journey.

Details about this study are discussed in this consent form. It is important that you understand this information so that you can make an informed choice about being in this research study. If you have any questions about this study at any time, you should ask the researchers named in this consent form. Their contact information is below.

Who qualifies for this study? Participants in this study should meet the following criteria: 1) Meet the criteria for and complete Phase 1 of this study (electronic survey packet); & 2) Volunteered to participate in Phase 2 semi-structured interviews.

What will you ask me to do if I agree to be in the study?

If you decide to participate in this study I will ask that you answer some interview questions over the phone. These questions ask you about different aspects of your wellbeing in cancer survivorship. Interviews are estimated to take between 45-90 minutes to complete, depending on the length of your responses and what you would like to share.

Is there any audio/video recording?

Approved IRB
8/29/16

If you consent to continue participating, you will complete a semi-structured interview with the researcher that will be audio recorded. Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be guaranteed although the researcher will try to limit access to the recording as described below.

What are the risks to me? The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risk to participants. The minimal risks may include emotional reactions to questions in the interview and are not expected to require medical or psychological treatment. Please know you have the option not to respond to any questions that cause you to feel uncomfortable or emotionally distressed.

If you feel any emotional distress, you are encouraged to seek counseling from a qualified professional. The following online database of counselors can assist you in locating a qualified professional: http://www.nbcc.org/CounselorFind.

If you have questions, want more information or have suggestions, please contact Hallie Sylvestro at (336) 334-3423 or email at hmkuruck@uncg.edu, or faculty advisor Keith Mobley, PhD, at k_mobley@uncg.edu.

If you have any concerns about your rights, how you are being treated, concerns or complaints about this project or benefits or risks associated with being in this study please contact the Office of Research Integrity at UNCG toll-free at (855)-251-2351.

Are there any benefits to society as a result of *me* taking part in this research? Your participation may help mental health and medical professionals better understand, assess, and support the psychosocial needs of cancer survivors. It is hoped the research will lead to a better understanding of improved psychosocial treatment and resources within cancer care to improve the wellbeing of cancer survivors and their families.

Are there any benefits to *me* for taking part in this research study? There are no direct benefits to participants in this study. However, participants in this phase of the study will be provided their written and graphical results from the surveys.

Will I get paid for being in the study? Will it cost me anything? Participants who voluntarily complete the semi-structured interview will receive an e-gift card valued at $10 to their choice of Starbucks, Target, or Panera. Participants who complete the semi-structured interviews will also receive a copy of their Phase 1 survey scores and a written summary of results.

How will you keep my information confidential? The information you share will be kept confidential. The interview will be audio recorded on a digital device and transferred to a password-protected computer then deleted from the digital device. Only the primary researcher will listen to the audio recording. The researcher will transcribe the interviews within 72 hours onto a password-protected computer, at which point the audio recording file will be deleted. Participants will be given a coded number to protect their confidentiality. Any narrative of the interview will not contain personal identifying

information. When the password protected computer is not in use, it will be stored behind a locked door. All information obtained in this study is strictly confidential unless disclosure is required by law.

What if I want to leave the study? You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data that has been collected be destroyed unless it is in a de- identifiable state. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

What about new information/changes in the study? If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

Voluntary Consent by Participant:

By checking this box f you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document, meet the study criteria, and are agreeing to participate in this study. All of your questions concerning this study have been answered. You are encouraged to print this page for your records before proceeding.

☐Yes, I have read and understood the consent form and voluntarily consent to participate in this study.

☐No, I do not wish to participate in this study.

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8/29/16

Social Media Message to Closed Group Administrators

Hello! You are receiving this message as an administrator of a social media cancer survivorship group. My name is Hallie Sylvestro, and I am currently working on my doctoral dissertation. I am also a mental health counselor who is passionate about supporting cancer patients and their families!

I am seeking participants for a study that will focus on non-biomedical factors of wellbeing, such as social, spiritual, and mental health factors. This study is aimed at improving how mental health and medical care providers support cancer survivors in improving their holistic wellness.

I am looking for participants who are: 1) at least 18 year of age; 2) currently be in partial or full remission from cancer; 3) be within three years of your date of diagnosis (any stage/type); 4) have undergone surgery, radiation, and/or chemotherapy during the course of cancer treatment.

For every completed survey packet, *the primary researcher with donate $1 to the LiveStrong Foundation,* a charitable foundation that supports research, education, and support services for individuals who have experienced cancer (LiveStrong.org).

If you would be willing, I ask that you create a post with the following wording and link on your group page:

Participants needed for study on wellbeing in cancer survivorship! For every completed survey packet, *the primary researcher will donate $1 to the LiveStrong Foundation.*

For more info: http://wellbeingandcancersurvivorship.weebly.com/

Thank you for your time and consideration!

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8/29/16

STUDY LANDING PAGE

Study Landing Page Link:
http://wellbeingandcancersurvivorship.weebly.com/

WELLBEING IN CANCER SURVIVORSHIP

You are invited to participate in a study about holistic wellbeing in cancer survivorship. This study will focus on non-biomedical factors of wellbeing, such as social, spiritual, and mental health factors. This study is aimed at improving how mental health and medical care providers support cancer survivors in improving their holistic wellness.

Participants should 1) be at least 18 year of age; **2)** currently be in partial or full remission from cancer; **3)** be within three years of your date of diagnosis (any stage/type); **4)** have undergone surgery, radiation, and/or chemotherapy during the course of cancer treatment.

This study should take 20-40 minutes.

For every completed survey packet, *the primary researcher with donate $1 to the LiveStrong Foundation,* a charitable foundation that supports research, education, and support services for individuals who have experienced cancer (LiveStrong.org).

What will I be asked to do? Complete an electronic survey packet that includes a demographic questionnaire and three assessments that will ask questions related to wellbeing during cancer survivorship.

If you complete the survey, you will also have the option to volunteer to be selected for a semi-structured interview in phase two of the study. Participants who complete the semi-structured interview will receive a $10 e-gift card to their choice of Starbucks, Target, or Panera.

To participate, click the following link:
https://uncg.qualtrics.com/SE/?SID=SV_6nAoDLq0oXrWoHH

After you have fully completed the survey, **please consider sharing my post with others :)**

If you have any questions, please contact me at hmkuruck@uncg.edu, affiliated with - The University of North Carolina at Greensboro.

Thank you for your time and consideration! Every cancer survivor has a story to tell.

Approved IRB
8/29/16

EMAIL RECRUITMENT FOR INTERVIEWS

Dear Participant,

Thank you for agreeing to participate in the interview for the study *Significant Psychosocial Factors Related to Holistic Wellbeing Among Cancer Survivors*.

I would like to invite you to participate in a semi-structured interview with me. The interview focuses on your experience of wellbeing as a cancer survivor, and is expected to take approximately 45 to 90 minutes.

You will receive the questions in advance of the interview and may select the day and time of the interview, which will be held over telephone. In exchange for your time and as a token of appreciation, you will receive a $10 gift card to your choice of Starbucks, Target, or Panera. Please specify times you may be willing to complete the interview, as well as your choice of gift card in a return email.

If you have questions you may contact the primary investigator/researcher, Hallie Sylvestro at hmkuruck@uncg.edu.

Please complete and return the informed consent via email. You are encouraged to print a copy of this form for your personal records.

Thank you for your time.

Sincerely,
Hallie Sylvestro, M.Ed., LPCA, NCC, Principal Investigator and Doctoral Candidate,
The University of North Carolina at Greensboro

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8/29/16

APPENDIX B

INSTRUMENTATION AND DEMOGRAPHIC QUESTIONNAIRE

Page

Demographic Questionnaire

1. Gender?
   - ☐ Male
   - ☐ Female
   - ☐ Prefer not to answer

2. Age? _____ (free space provided)

3. Date of Diagnosis? _____

4. Diagnosis Type (e.g., breast, lung)? _____

5. Stage?
   - ☐ I
   - ☐ II
   - ☐ III
   - ☐ IV

6. Treatments Received (check all that apply)?
   - ☐ Surgery
   - ☐ Chemotherapy
   - ☐ Radiation
   - ☐ Other _____

7. Remission Status?
   - ☐ Full Remission
   - ☐ Partial Remission

8. Length of Time in Remission (#months)? _____

9. Race?
   - ☐ Black-Non-Hispanic
   - ☐ American Indian/Alaskan Native
   - ☐ Hispanic
   - ☐ Asian/Pacific Islander
   - ☐ White- Non Hispanic
   - ☐ Other _____

10. Relationship Status?
- ☐ Single
- ☐ In a committed relationship (married or partnered)
- ☐ Separated
- ☐ Widowed
- ☐ Divorced
- ☐ Other _____

11. Number of Housemates (including self)?
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5+

12. Employment Status
- ☐ Employed
- ☐ Currently on leave
- ☐ Unemployed
- ☐ Homemaker
- ☐ Retired
- ☐ Student
- ☐ Other _____

The Functional Assessment of Cancer Therapy Scale

FACT-GP (Version 4)

Below is a list of statements that other people have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	PHYSICAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

FACT-GP (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	EMOTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

The Five-Factor Wellness Inventory

Five Factor Wel Inventory
Form A2

The purpose of this inventory is to help you make healthy lifestyle choices. The items are statements that describe you. Answer each item in a way that is true for you **most of the time. Think about how you most often see yourself, feel or behave.** Answer all the items. Do not spend too much time on any one item. Your honest answers will make your scores more useful.

Name: _____	Gender: _____
Highest grade completed: _____	Birth Date: _____
ID #: _____	

Mark only one answer for each item using this scale:

Strongly Agree	If it is true for you most or all of the time
Agree	If it is true for you some of the time
Disagree	If it is usually not true for you
Strongly Disagree	If it is almost or never true for you

EXAMPLE

	Strongly Agree	Agree	Disagree	Strongly Disagree
I like meeting new people.	A	X	C	D

A. Strongly Agree **B. Agree** **C. Disagree** **D. Strongly Disagree**

1.	I engage in a leisure activity in which I lose myself and feel like time stands still.	A	B	C	D
2.	I am satisfied with how I cope with stress.	A	B	C	D
3.	I eat a healthy amount of vitamins, minerals and fiber each day.	A	B	C	D
4.	I often see humor even when doing a serious task.	A	B	C	D
5.	I am satisfied with the quality and quantity of foods in my diet.	A	B	C	D
6.	Being a male/female is a source of satisfaction and pride to me.	A	B	C	D
7.	When I have a problem, I study my choices and possible outcomes before acting.	A	B	C	D
8.	I do not drink alcohol or drink less than two drinks per day.	A	B	C	D
9.	I get some form of exercise for 20 minutes at least three times a week.	A	B	C	D
10.	I value myself as a unique person.	A	B	C	D
11.	I have friends who would do most anything for me if I were in need.	A	B	C	D
12.	I feel like I need to keep other people happy.	A	B	C	D
13.	I can express both my good and bad feelings appropriately.	A	B	C	D
14.	I eat a healthy diet.	A	B	C	D
15.	I do not use tobacco.	A	B	C	D
16.	My cultural background enhances the quality of my life.	A	B	C	D
17.	I have a lot of control over conditions affecting the work or schoolwork I do.	A	B	C	D
18.	I am able to manage my stress.	A	B	C	D
19.	I regularly get enough sleep.	A	B	C	D
20.	I can take charge and manage a situation when it is appropriate.	A	B	C	D
21.	I can laugh at myself.	A	B	C	D
22.	Being male/female has a positive effect on my life.	A	B	C	D
23.	My free time activities are an important part of my life.	A	B	C	D
24.	My work or schoolwork allows me to use my abilities and skills.	A	B	C	D
25.	I have friends and/or relatives who would provide help for me if I were in need.	A	B	C	D
26.	I have at least one close relationship that is secure and lasting.	A	B	C	D
27.	I seek ways to stimulate my thinking and increase my learning.	A	B	C	D
28.	I am often unhappy because my expectations are not met.	A	B	C	D
29.	I look forward to the work or schoolwork I do each day.	A	B	C	D
30.	I usually achieve the goals I set for myself.	A	B	C	D

A. Strongly Agree **B. Agree** **C. Disagree** **D. Strongly Disagree**

31.	I have sources of support with respect to my race, color, or culture.	A	B	C	D
32.	I can find creative solutions to hard problems.	A	B	C	D
33.	I think I am an active person.	A	B	C	D
34.	I take part in leisure activities that satisfy me.	A	B	C	D
35.	Prayer or spiritual study is a regular part of my life.	A	B	C	D
36.	I accept how I look even though I am not perfect.	A	B	C	D
37.	I take part in organized religious or spiritual practices.	A	B	C	D
38.	I am usually aware of how I feel about things.	A	B	C	D
39.	I jump to conclusions that affect me negatively, and that turn out to be untrue.	A	B	C	D
40.	I can show my feelings at any time.	A	B	C	D
41.	I make time for leisure activities that I enjoy.	A	B	C	D
42.	Others say I have a good sense of humor.	A	B	C	D
43.	I make it a point to seek the views of others in a variety of ways.	A	B	C	D
44.	I believe that I am a worthwhile person.	A	B	C	D
45.	I feel support from others for being a male/female.	A	B	C	D
46.	It is important for me to be liked or loved by everyone I meet.	A	B	C	D
47.	I have at least one person who is interested in my growth and well-being.	A	B	C	D
48.	I am good at using my imagination, knowledge, and skills to solve problems.	A	B	C	D
49.	I can start and keep relationships that are satisfying to me.	A	B	C	D
50.	I can cope with the thoughts that cause me stress.	A	B	C	D
51.	I have spiritual beliefs that guide me in my daily life.	A	B	C	D
52.	I have at least one person with whom I am close emotionally.	A	B	C	D
53.	I am physically active most of the time.	A	B	C	D
54.	I use humor to gain new insights on the problems in my life.	A	B	C	D
55.	I can put my work or schoolwork aside for leisure without feeling guilty.	A	B	C	D
56.	I have to do all things well in order to feel worthwhile.	A	B	C	D
57.	I feel a positive identity with others of my gender.	A	B	C	D
58.	I am appreciated by those around me at work or school.	A	B	C	D
59.	I plan ahead to achieve the goals in my life.	A	B	C	D
60.	I like myself even though I am not perfect.	A	B	C	D
61.	I am satisfied with my free time activities.	A	B	C	D
62.	I do some form of stretching activity at least three times a week.	A	B	C	D
63.	I eat at least three meals a day including breakfast.	A	B	C	D
64.	I do not use illegal drugs.	A	B	C	D

65.	I believe in God or a spiritual being greater than myself.	A	B	C	D
66.	I can experience a full range of emotions, both positive and negative.	A	B	C	D
67.	I view change as an opportunity for growth.	A	B	C	D
68.	I eat fruits, vegetables and whole grains daily.	A	B	C	D
69.	My spiritual growth is essential to me.	A	B	C	D
70.	When I need information, I have friends whom I can ask for help.	A	B	C	D
71.	I am proud of my cultural heritage.	A	B	C	D
72.	It is important for me to be physically fit.	A	B	C	D
73.	I have at least one person in whom I can confide my thoughts and feelings.	A	B	C	D
74.	I am satisfied with my life.	A	B	C	D
75.	I have enough money to do the things I need to do.	A	B	C	D
76	I feel safe in my home.	A	B	C	D
77.	I feel safe in my workplace or school.	A	B	C	D
78.	I feel safe in my neighborhood.	A	B	C	D
79.	I feel safe in my daily life.	A	B	C	D
80.	I am afraid that I or my family will be hurt by terrorists.	A	B	C	D
81.	I am optimistic about the future.	A	B	C	D
82.	My government helps me be more well.	A	B	C	D
83.	My education has helped me be more well.	A	B	C	D
84.	My religion helps me be more well.	A	B	C	D
85.	I know I can get a suitable job when I need one.	A	B	C	D
86.	I watch TV less than two hours each day.	A	B	C	D
87.	World peace is important to my well-being.	A	B	C	D
88.	Other cultures add to my well-being.	A	B	C	D
89.	I look forward to growing older	A	B	C	D
90.	I like to plan the changes in my life.	A	B	C	D
91.	Changes in life are normal.	A	B	C	D

Center for Epidemiologic Studies Short Depression Scale

Below is a list of some of the ways you may have felt or behaved.

Please indicate how often you have felt this way during the past week by checking the appropriate box for each question.

	Rarely or none of the time (less than 1 day)	**Some or a little of the time** (1-2 days)	**Occasionally or a moderate amount of time** (3-4 days)	**All of the time** (5-7 days)
1. I was bothered by things that usually don't bother me.	☐	☐	☐	☐
2. I had trouble keeping my mind on what I was doing.	☐	☐	☐	☐
3. I felt depressed.	☐	☐	☐	☐
4. I felt that everything I did was an effort.	☐	☐	☐	☐
5. I felt hopeful about the future.	☐	☐	☐	☐
6. I felt fearful.	☐	☐	☐	☐
7. My sleep was restless.	☐	☐	☐	☐
8. I was happy.	☐	☐	☐	☐
9. I felt lonely.	☐	☐	☐	☐
10. I could not "get going."	☐	☐	☐	☐

APPENDIX C

IRB APPROVAL

Page

To: Hallie Sylvestro
Counsel and Ed Development

From: UNCG IRB

Date: 8/29/2016

RE: Notice of IRB Exemption
Exemption Category: 2.Survey, interview, public observation
Study #: 16-0279

Study Title: Significant Psychosocial Factors Related to Holistic Wellbeing Among Cancer Survivors

This submission has been reviewed by the IRB and was determined to be exempt from further review according to the regulatory category cited above under 45 CFR 46.101(b).

Study Description:

Increasing cancer rates as well as significant improvements in bio-medical treatment of cancer have led to an increase of cancer survivors. However, despite improvements in medical care, multiple significant research studies and national panels have identified a lack of attention to to non-bio-medical facets of holistic wellbeing in cancer care, as well as a strong need for improved assessment and treatment of mental health symptomology among cancer patients and survivors. The purpose of this study is to utilize a mixed method design to explore significant psychosocial factors related to holistic wellbeing in cancer survivorship. This study will explore psychosocial wellbeing through two disciplinary models of wellbeing, and will compare findings to the self-reported psychosocial needs and experiences of cancer survivors.

Regulatory and other findings:

- This research meets criteria for waiver of a signed consent form according to 45 CFR 46.117(c)(2).

Investigator's Responsibilities

- This research meets criteria for waiver of a signed consent form according to 45 CFR 46.117(c)(2).

Investigator's Responsibilities

Please be aware that any changes to your protocol must be reviewed by the IRB prior to being implemented. Please utilize the most recent and approved version of your consent form/information sheet when enrolling participants. The IRB will maintain records for this study for three years from the date of the original determination of exempt status.

Signed letters, along with stamped copies of consent forms and other recruitment materials will be scanned to you in a separate email. **Stamped consent forms must be used unless the IRB has given you approval to waive this requirement.** Please notify the ORI office immediately if you have an issue with the stamped consents forms.

Please be aware that valid human subjects training and signed statements of confidentiality for all members of research team need to be kept on file with the lead investigator. Please note that you will also need to remain in compliance with the university "Access To and Retention of Research Data" Policy which can be found at http://policy.uncg.edu/university-policies/research_data/.

CC:
Allen Mobley, Counsel and Ed Development